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**The development and testing of a behavioural change
intervention to increase physical activity,
predominantly through walking, after stroke**

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**Doctor of Philosophy
The University of Edinburgh
2017**

ABSTRACT

Introduction

Globally stroke remains the leading cause of adult disability. An aging population and a reduction in stroke case fatality has led to an increasing number of people living with stroke i.e. stroke survivors. The ability to perform important day-to-day activities, such as walking and housework, is frequently impaired in stroke survivors. Therefore, it has become essential to address the long-term needs of stroke survivors, prompting focussed research on life after stroke.

A reduction in physical fitness after stroke may contribute to stroke related disability.

It is possible to improve physical fitness by regular, structured physical activity.

Improving physical fitness after stroke and increasing physical activity are aspects of life after stroke that are increasingly being researched. Although the evidence base for the benefits of physical fitness training is growing, research has indicated that benefits gained are not always maintained at follow-up. To facilitate the uptake and maintenance of physical activity after stroke, it is essential to understand why many stroke survivors do not undertake regular physical activity. Understanding this difficult concept will enable the tailoring of behaviour change interventions to promote and maintain physical activity after stroke. However, there has been limited work in developing theory driven behaviour change interventions to increase physical activity in stroke survivors.

Therefore, the aim of this thesis was to develop and test a behaviour change intervention to increase physical activity after stroke.

Methods

In order to address the above aim, six interlinking studies were conducted within the development and feasibility stages of the MRC framework for the development of complex interventions. A systematic review (study one) examined barriers and facilitators to physical activity perceived by stroke survivors. This study showed a lack of literature in this area, and that the already published studies had limited generalisability to the UK stroke population. Therefore, it was deemed appropriate to conduct a qualitative study (study two) to examine the perceived barriers and facilitators to physical activity in the local stroke population. Both studies one and two highlighted the influence of self-efficacy towards increasing physical activity. As part of earlier work conducted prior to this PhD, there was previously unanalysed data on perceived barriers and facilitators to physical activity after stroke. These quantitative data encompassed specific questions exploring self-efficacy and intention to physical activity post stroke. In light of the evidence it was deemed necessary to analyse these data (study three). It was envisaged that the behaviour change intervention would incorporate a feedback device, so participants could clearly see how much daily physical activity they were undertaking. An opportunity arose to collaborate with a team at Newcastle University who had developed an accelerometer that incorporated an immediate feedback screen. Therefore, a device validation study was conducted as study four. Results from studies one to four were combined, with the use of the Theoretical Domains Framework, and the behaviour change intervention was developed. Two uncontrolled pilot studies (studies five and six) were conducted to determine the feasibility and acceptability of the behaviour change intervention to the stroke population.

Results

The systematic review included six articles, providing data on 174 stroke survivors. Commonly reported barriers were environmental factors, health concerns and stroke impairments. Commonly reported facilitators were social support and the need to be able to perform daily tasks. Qualitative interviews were conducted with 13 stroke survivors, at which point data saturation was reached. The most commonly reported TDF domains were 'beliefs about capabilities', 'environmental context and resources' and 'social influence'. The quantitative study provided data from 50 stroke survivors. Intention and self-efficacy were high, with self-efficacy graded as either 4 or 5 (highly confident) on a five-point scale by [34 (68%)] participants, whilst 42 (84%) participants "strongly agreed" or "agreed" that they intended to increase their walking after their stroke.

Ten participants were recruited to validate the new accelerometer. Mean time since stroke was 29 days (SD =27.9 days). The 10 participants walked a mean distance of 245 meters (SD=129m) and their mean walking speed was 0.79ms^{-1} (SD=0.34 ms^{-1}). The Culture Lab were unable to develop the accelerometer in the necessary time frame and therefore no accelerometer was available for trialling the behaviour change intervention. Therefore, pedometers were used to record step count during the behaviour change intervention.

A total of four participants took part in the 12 week behaviour change intervention, over two study periods. All participants managed to increase their step counts during this time. The studies had problems both with recruitment and retention of participants. These issues have been discussed.

Conclusions

This work has enhanced the understanding of the barriers and facilitators perceived by stroke survivors to increase physical activity. This work has allowed the development of a theoretically driven, complex behaviour change intervention that was successfully trialled with a small group of stroke survivors. Areas of further research have been discussed.

LAY SUMMARY

Stroke is a leading cause of death and disability within the United Kingdom.

Physical activity after stroke is low. Evidence suggests increasing physical activity may reduce disability and secondary strokes. The best way to increase physical activity after stroke remains unclear. A programme to support people to become more active after stroke may lead to long-term increases in physical activity. The content of such programmes needs to be established. Therefore, the aim of this work was to develop and test materials to support people who have had a stroke to become more active, predominantly through walking.

To develop the exercise programme, preliminary studies were conducted to determine the barriers and facilitators to physical activity perceived by stroke survivors and the key “ingredients” to the intervention. Once the components of the intervention had been determined, the ease of carrying out the intervention and how well it was tolerated and accepted by stroke survivors was tested. In total four participants took part in the 12 week intervention, over two study periods. All participants successfully increased their walking during this time. There were challenges recruiting people into the programme and supporting those who started the programme to continue.

This work has helped to understand what helps and hinders stroke survivors to increase their physical activity. This work has developed an exercise programme, guided by research, and was successfully tested with a small group of stroke survivors. Areas of further research have been discussed.

KEY WORDS

Stroke, physical activity, behaviour change

ACKNOWLEDGMENTS

Prof Gillian Mead: I would like to express my gratitude for your support, guidance and encouragement throughout this work. Your involvement in all studies within this work is much appreciated. Thank you for taking the time to read and comment on my thesis at varying stages, and always being there on email when I need guidance.

Dr Carolyn Greig: Thank you for your support throughout my PhD and taking the time to read and comment on my thesis. Your guidance has been greatly valued and I am thankful to have had your support throughout my PhD.

Emeritus Professor Marie Johnston: Thank you for always challenging my thinking and providing me with continued support and encouragement throughout my PhD. Thank you for always taking the time to answer my emails and welcoming me into the Aberdeen University Health Psychology Group to further my understanding for Health Psychology.

Emeritus Professor Derek Johnston: Thank you for taking the time to read and comment on the papers I have published from this PhD, and welcoming me into the Aberdeen University Health Psychology Group.

Professor Falko Sniehotta: Thank you for always supporting me throughout my PhD, for answering any queries I may have and for welcoming me into the Newcastle University Health Psychology Group.

Emeritus Professor Marie Donaghy: Thank you for the support you gave me in analysing the qualitative research study. Your help and guidance throughout the analysis process ensured the analysis was a straightforward and interesting process.

The Stroke Association: Thank you for the Junior Research Fellowship that allowed me to complete this PhD.

The University of Edinburgh: I acknowledge and thank The University of Edinburgh for providing me with a staff scholarship that supported this work.

Local NHS team and research nurses: Thank you for your support in helping me to identify and recruit suitable participant for my studies.

Friends and family: Thank you for supporting me throughout this journey and not letting me give up when times have been hard. Although a lot has changed since I began my PhD, the love and encouragement you have given me has kept me strong and allowed me to complete this work.

DECLARATION

I declare that this thesis has been composed solely by myself and that it has not been submitted, in whole or in part, in any previous application for a degree. Except where states otherwise by reference or acknowledgment, the work presented is entirely my own. Permission has been granted to include the publications arising from this thesis by each of the publishing journals. The contribution of the co-authors to each of these publications has been acknowledged at the beginning of each of the publication chapters.

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LIST OF ABBREVIATIONS

2MWT	2 Minute Walk Test
6MWT	6 Minute Walk Test
BCT	Behaviour change technique
BMI	Body Mass Index
CHD	Coronary Heart Disease
CHI	Community Health Index Number
CHIEF	Craig Hospital Inventory of Environmental Factors
CI	Confidence Interval
CT	Computed Tomography
CVA	Cerebral Vascular Accident
DALYs	Disability-Adjusted Life-Years
EMG	Electromyography
eNOS	Endothelial nitric oxide synthase
EQ-5D-5L	Euro-Qol 5D
FAS	Fatigue Assessment Scale
HADS	Hospital Anxiety and Depression Scale
HDL	High-Density Lipoprotein
HR	Hazard Ratio
ICF	International Classification of Functioning, Disability and Health
ICH	Intracerebral Haemorrhage
IQR	Interquartile Range
LACS	Lacunar Circulatory Syndrome
LDL	Low-Density Lipoprotein
MD	Mean Difference
MeSH	Medical Subject Headings
MOCA	Montreal Cognitive Assessment
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
NEADL	Nottingham Extended Activities of Daily Living

NHS	National Health Service
OR	Odds Ratio
OCSP	Oxford Community Stroke Project
PACS	Partial Anterior Circulatory Syndrome
POCS	Posterior Circulatory Syndrome
RCT	Randomised Controlled Trial
RR	Relative Risk
SAH	Subarachnoid Haemorrhage
SD	Standard Deviation
SMD	Standardised Mean Difference
SPPB	Short Physical Performance Battery
TACS	Total Anterior Circulatory Syndrome
TDF	Theoretical Domains Framework
UK	United Kingdom
USA	United States of America
VO2 MAX	maximal oxygen consumption

LIST OF PUBLICATIONS

It should be noted that 'Carroll' was student's maiden name. Publications discussed in this thesis that precede the PhD are published by the same author as 'Nicholson'.

1. **NICHOLSON, SL.**, GREIG, CA., SNIEHOTTA, F., JOHNSTON, M., LEWIS, SJ., MCMURDO, MET., JOHNSTON, D., SCOPES, J. and MEAD, GE. 2017. Quantitative data analysis of perceived barriers and motivators to physical activity in stroke survivors. *J R Coll Physicians Edinb.* 47, 231-236
2. **NICHOLSON, SL.**, GREIG, CA., SNIEHOTTA, F., JOHNSTON, M., LEWIS, SJ., MCMURDO, MET., JOHNSTON, D., SCOPES, J. and MEAD, GE. European Stroke Organisation Conference. *Quantitative analysis of the perceived barriers and motivators to physical activity post stroke.* [Poster presentation]. Glasgow: April 2015
3. **NICHOLSON, SL.**, DONAGHY, M., JOHNSTON, M., SNIEHOTTA, FF., VAN WIJCK, F., JOHNSTON, D., GREIG, C., MCMURDO, MET. and MEAD, G. 2013. A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity. *Disabil Rehabil.* 36, 1857-68
4. FIELD, MJ., GEBRUERS, N., SUNDARAM, TS., **NICHOLSON, S.** and MEAD, G. 2013. Physical Activity after Stroke: A Systematic Review and Meta-Analysis. *ISRN Stroke*, Article ID 464176. doi:10.1155/2013/464176

5. **NICHOLSON, S.**, SNIEHOTTA, FF., VAN WIJCK, F., GREIG, CA., JOHNSTON, M., MCMURDO, MET., DENNIS, M. and MEAD, GE. 2013. A systematic review of perceived barriers and motivators to physical activity after stroke. *Int J Stroke*. Jul;8(5):357-64. doi: 10.1111/j.1747-4949.2012.00880.x.
6. **CARROLL, S.**, DONAGHY, M., JOHNSTON, M., JOHNSTON, DW., SNIEHOTTA, FF., VAN WIJCK, F., GREIG, C., MCMURDO, MET., DENNIS, M. and MEAD, GE. UK Society for Behavioural Medicine. *Barriers and motivators to physical activity among stroke survivors*. [Oral presentation]. Stirling: October 2011
7. **CARROLL, S.**, SNIEHOTTA, F., VAN WIJCK, F., GREIG, C. and MEAD, G. UK Stroke Forum. *A systematic review of perceived barriers and motivators to physical activity after stroke*. [Poster Presentation] Glasgow: November 2011. International Journal of Stroke. Special Issue: UK Stroke Forum 2011 Abstracts, 29 November 2011–1 December 2011, [Volume 6, Issue Supplement s2](#), pages 66–68, December 2011

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CHAPTER 1 Introduction

The first part of this PhD thesis introduces the background to the three core topics of this body of work: stroke, physical activity and behaviour change.

Each of these three core topics will be discussed individually before amalgamating them and forming the formal aims and objectives of this PhD thesis.

1.1. Stroke

The World Health Organisation defines stroke as “rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin” (Investigators, 1988). Stroke is a clinical syndrome with three main pathologic types (ischaemic stroke, intracerebral haemorrhage [ICH], and subarachnoid haemorrhage [SAH]). Each pathologic type has several subtypes with distinct underlying vascular pathologies (Adams et al., 1993). Ischaemic stroke can be extra-cranial or intracranial and is caused by embolisms from a cardiac source or small vessel disease. Approximately 87% of strokes are ischaemic (Mozaffarian et al., 2015). Haemorrhagic stroke accounts for approximately 13% of strokes and is the accumulation of blood anywhere within the skull due to a burst blood vessel, which compresses the surrounding brain tissue (Mozaffarian et al., 2015).

The manifestation of stroke depends on the location of the infarct or haemorrhage within the brain. Clinical features of stroke include: hemiplegia/hemiparesis, ataxia, sensory loss, expressive and/or receptive dysphasia, inattention, neglect, dysphagia and dysarthria. However, emotions and cognition can also be affected by stroke.

1.2. Prevalence and incidence of stroke

1.2.1. Prevalence

Within the United Kingdom (UK) there are 1.2 million stroke survivors (The Stroke Association, 2017). As a disease of ageing, the global prevalence of stroke is expected to increase significantly in the years ahead as the elderly population (over 65 years of age) continues to increase by approximately 9 million people per year (Mukherjee and Patil, 2011). Growth in this age group is projected to continue for the foreseeable future, with the number of people aged 65 years or over expected to reach 16.9 million by 2035 (Rutherford, 2012). In Scotland the average age for men to have a stroke is 71 and the average age for women to have a stroke is 76. In the rest of the UK the average age for men to have a stroke is 74 and the average age for women to have a stroke is 80 (The Stroke Association, 2017). The age and sex standardised mortality rate for stroke has decreased over the last 10 years, from 89.9 per 100,000 population in 2004 to 52.8 per 100,000 in 2013, a reduction of 41.2% over 10 years (ISD, 2015). During this time period the reduction in age and sex standardised mortality rates for stroke has been greater for males (43.1%) than females (39.3%) (ISD, 2015).

Due to the increase in the elderly population and the reduction in stroke mortality, more and more people are surviving a stroke but are often left to deal with serious, life-changing disabilities. Stroke is ranked the second most common cause of death, and the third most common cause of disability-adjusted life-years (DALYs) worldwide (Feigin et al., 2014).

1.2.2. Incidence

Globally, first time stroke affects about 17 million people each year (Feigin et al., 2014). The incidence (i.e., the number of new cases) rises sharply with age, predominantly occurring in middle age and older adults. Approximately 80% of first time strokes will occur over the age of 65 years with the average age of first time stroke approximately 75 years (Syme et al., 2005, Rudd, 2009). However, a recent study has reported a decline in the average age of stroke from 71.2 years in 1993 to 69.2 years in 2005 ($p < 0.0001$) (Kissela et al., 2012).

A systematic review of 56 population-based studies has shown that stroke incidence among high-income countries has decreased by 42% over the past four decades (Feigin et al., 2009). In the United Kingdom alone, stroke incidence has fallen by 30% between 1999 and 2008 (Lee et al., 2011a). The Information Services Division (2015) has reported that the incidence rate of cerebrovascular disease in Scotland was 328.9 per 100,000 population in 2004/05 compared with 257.4 per 100,000 in 2013/14, a decrease of 21.8%.

Stroke incidence is strongly related to age. The age and sex standardised rate for the under 75s in 2013/14 was 123.0 per 100,000 population and for those aged 75 years and over for the same period it was 1,616.6 per 100,000 population (ISD, 2015). The reduction in stroke incidence in the Western World has been attributed to more effective treatment of stroke risk factors (Rothwell et al., 2004) (Islam et al., 2008). Treatment of risk factors is essential to reduce the number of first and subsequent strokes of all types (Furie et al., 2011) (Goldstein et al., 2011).

1.3. Risk factors

Although non-modifiable risk factors such as age, sex, genetics and ethnicity play a role in the incidence of stroke, there are several modifiable risk factors that can be managed through lifestyle adjustments and pharmacological therapies (Furie et al., 2011). These modifiable risk factors will now be looked at individually.

1.3.1. Hypertension

Hypertension (blood pressure of 140/90 mmHg or higher) is the leading independent risk factor for all types of stroke (Furie et al., 2011) (Castilla-Guerra and Fernandez-Moreno Mdel, 2012). A meta-analysis of 40 randomised controlled trials [RCTs] involving 188,000 participants has shown a 30- 40% stroke risk reduction by pharmacologically lowering systolic blood pressure by 10mmHg (Lawes et al., 2004). Furthermore, a meta-analysis including 16 trials and involving 70,664 participants has shown a 22% reduction in first ever stroke, in participants with pre-hypertensive blood pressures, with the use of antihypertensive drugs (Sipahi et al., 2012).

1.3.2. Diabetes

Diabetes is an independent risk factor for ischaemic stroke, but less evidence supports diabetes as a risk factor for recurrent and haemorrhagic stroke (Furie et al., 2011) (Megherbi et al., 2003). Analysis from a systematic review of 64 studies representing 775,385 individuals and 12,539 fatal and non-fatal strokes found that the pooled maximum-adjusted relative risk [RR] of stroke associated with diabetes was 2.28 (95% confidence interval [CI] 1.93–2.69) in women and 1.83 (1.60–2.08)

in men. This sex differential was seen consistently across major predefined stroke, participant and study subtype. The pooled ratio of RRs was 1.27 (1.10–1.46; $I^2=0$) (Peters et al., 2014)

1.3.3. Smoking

Data from a review of 81 prospective cohort studies including 3,980,359 participants and 42,401 stroke survivors found smoking to be an independent risk factor for all stroke types in both males and females (Peters et al., 2013). Compared to non-smoking, current smoking was associated with an increased risk of ischemic stroke by 54% (95% CI, 1.21–1.96) in females and 53% (95% CI, 1.28–1.82) in males. For haemorrhagic stroke, the increased risk associated with current smoking was 63% (95% CI, 1.21–2.19) in females and 22% (95% CI, 0.98–1.51) in males (Peters et al., 2013).

1.3.4. Obesity

Obesity is an independent risk factor for ischaemic stroke in both genders and in different ethnic populations (Yatsuya et al., 2010) (Lee et al., 2011b) (Bazzano et al., 2010). Thus, the American Heart Association and the American Stroke Association recommend the treatment of obesity for both primary and secondary stroke prevention of stroke (Goldstein et al., 2011). A meta-analysis reported that the RR for ischaemic stroke was 1.22 (95% CI: 1.05–1.41) for overweight and 1.64 (95% CI: 1.36–1.99) for obese patients (Strazzullo et al., 2010). A significant relationship between obesity and haemorrhagic stroke has also been reported (Bazzano et al., 2010). After adjustment for age, gender, physical inactivity, urbanisation, geographic

variation, cigarette smoking, diabetes, and education, compared with participants of normal weight (body mass index [BMI] 18.5–24.9), relative hazard (95% CI) of incidence of haemorrhagic stroke was 1.00 (0.89–1.13) for participants who were underweight (BMI < 18.5), 1.18 (1.06–1.31) for those who were overweight (BMI 25–29.9), and 1.54 (1.27–1.87) for those who were obese (BMI \geq 30) (Bazzano et al., 2010). However, a recent pooled analysis of 97 prospective cohort studies including 31,093 stroke participants found interventions that reduce high blood pressure, cholesterol, and glucose might address approximately three-quarters of excess risk of stroke associated with obesity (Lu et al., 2014). Hazard ratios [HR] for each 5 kg/m² higher body mass index was 1.18 (1.14–1.22) for stroke after adjustment for confounders. Additional adjustment for the three metabolic risk factors reduced the HR to 1.04 (1.01–1.08) for stroke, suggesting that 76% of the excess risk of obesity for stroke is mediated by these metabolic risk factors (Lu et al., 2014).

1.3.5. Dyslipidemia

High blood cholesterol is an independent risk factor for both haemorrhagic and ischaemic stroke (Furie et al., 2011). A systematic review and meta-analysis of 23 prospective studies including 1,430,141 participants and 7,960 haemorrhagic strokes has shown that total cholesterol is inversely associated with risk of haemorrhagic stroke (Wang et al., 2013). High-density lipoprotein [HDL] cholesterol was positively associated with risk of intracerebral haemorrhage while, higher low-density lipoprotein [LDL] cholesterol was associated with lower risk of haemorrhagic stroke (Wang et al., 2013).

Results from a meta-analysis of statin use, including 165,792 individuals, has shown that each mmol/L decrease in LDL equates to a reduction in RR for all strokes by

21.1% (CI 6.3–33.5, $p=0.009$) (Amarenco and Labreuche, 2009). In secondary prevention of non-cardioembolic stroke, reduction of LDL also significantly reduced the risk of recurrent stroke (RR= 0.84, CI=0.71–0.99, $p=0.03$) (Amarenco and Labreuche, 2009).

1.3.6. Physical inactivity

A meta-analysis including 13 studies of self-reported physical activity and stroke found that physical activity reduced the risk of all types of first ever stroke (Diep et al., 2010). For men there was a 12% reduction in stroke risk associated with moderate intensity physical activity (RR = 0.88, CI 0.82-0.94, $p < 0.01$) and 19% reduction in risk of first stroke with high intensity physical activity (RR = 0.81, CI 0.75-0.87, $p < 0.01$). A 24% reduction in risk of first ever stroke was found in women who were exercising vigorously (RR = 0.76, CI=0.64-.89, $p < 0.01$). There was, however, no significant risk reduction associated with moderate intensity physical activity in women (Diep et al., 2010). An earlier systematic review had also found a risk reduction in both ischaemic and haemorrhagic stroke for those with high levels of physical activity compared with those who only participate in low levels of physical activity (Lee et al., 2003). As physical activity is a key component of this body of work it will be looked at in greater detail in section 1.6 of this thesis.

1.4. Impact of stroke

Worldwide stroke accounts for approximately 5.5 million deaths annually, with 44 million DALYs lost (Mukherjee and Patil, 2011). Stroke is the fourth most common cause of death within the UK and the most common cause of severe disability. In the UK stroke occurs more than 100,000 times each year (The Stroke Association, 2017).

The direct cost of stroke to the National Health Service [NHS] is estimated at £4 billion annually, increasing to £9 billion when informal care and loss of productivity are taken into account (Saka et al., 2009). Approximately one third of strokes each year are recurrent strokes (Hackam and Spence, 2007). These statistics indicate the financial burden of stroke to the UK.

Research has shown that the prevalence of stroke patients dying within the first 30 days after stroke has fallen from 20% to 12.5% between 2010 and 2016 (SIGN, 2010). Therefore, more people are living with residual stroke impairments and disability. One third of stroke survivors have residual disability after one year, causing them to be dependent on others. This residual disability may vary from moderate to severe, can manifest as physical or cognitive disability and can alter a stroke survivor's recovery (Mukherjee and Patil, 2011). Therefore, the impact of stroke is likely to increase due to the increasing prevalence of stroke, an ageing population and better acute treatments, such as thrombolysis, meaning more people survive their initial stroke but may be left with severe disability. The process of recovery after stroke is discussed in the following section.

1.5. Recovery after stroke

1.5.1. Mechanism of recovery

A primary concern immediately after stroke for patients, their relatives and their caregivers is the prospects of recovery. Stroke recovery can be influenced by the nature and severity of the initial deficit. Some degree of spontaneous recovery is usually seen in the weeks after stroke onset, demonstrating the restoration of

neurotransmission in tissue surrounding an infarct or haemorrhage. These processes include resolution of local swelling, re-absorption of local toxins, improvement of local circulation and recovery of partially damaged ischemic neurons (Bruno-Petrina, 2014). However, there is substantial variability in recovery post stroke (Kreisel et al., 2007). The second recovery mechanism, which may continue for many months, is neuroplasticity. Brain plasticity is the ability of the nervous system to modify its structural and functional organisation. The two most likely forms of plasticity are collateral sprouting of new synaptic connections and unmasking of previously latent functional pathways (Bruno-Petrina, 2014). Experimental evidence indicates that plasticity can be altered by the manipulation of environmental, behavioural and pharmacologic contexts which can influence cerebral reorganisation and consequently the recovery of function (Bruno-Petrina, 2014). A key aspect of neuroplasticity that has important implications for recovery, is that the changes in neuronal networks are use-dependent. Currently, it is recognised that repeated participation by patients in active physical therapeutic programmes may provide direct influence on the process of functional reorganisation in the brain and enhances neurologic recovery (Bruno-Petrina, 2014).

Physical activity can reduce inflammatory processes and apoptotic marker expression, promote brain angiogenesis and expression of some growth factors (Pin-Barre and Laurin, 2015). Physical activity can also maximise or accelerate neuroplasticity and motor recovery, but the underlying mechanisms remain unclear (Pin-Barre and Laurin, 2015). Animal studies have suggested that physical activity may up-regulate endothelial nitric oxide synthase (eNOS) and improve recovery post

stroke (Gertz et al., 2006). A systematic review and meta-analysis examined 40 studies (35 within the meta-analysis) to determine the effect of exercise in animal models of ischemic stroke where outcomes were measured as infarct volume, neurobehavioral score, neurogenesis, or a combination of these (Egan et al., 2014). The systematic review and meta-analysis found that exercise reduced overall infarct size by 25.2% (CI = 19.0%-31.3%) with pre-ischemic exercise reducing infarct volume by 42.2% (CI = 25.0%-59.3%,) and post-ischemic exercise reducing infarct volume by 18.9% (12.4%-25.5%) (Egan et al., 2014). In this review the optimal exercise regime was not clear. For infarct volume, forced exercise regimens were more effective than voluntary exercise, whereas the reverse was true for neurobehavioral outcome. For both outcomes, treadmill exercise appeared to be the most effective (Egan et al., 2014). There were insufficient data to analyse any effect of the amount of exercise undertaken or to allow multivariate analysis of the influence of study design factors (Egan et al., 2014). Animal studies of stroke provide cellular and molecular insights into events underlying stroke recovery (Cramer, 2008). Although this is a relatively understudied area, this literature indicates the importance of physical activity after stroke and its importance as an effective rehabilitation tool.

1.5.2. Pattern of recovery from different deficits

Recovery after stroke is variable, however physical activity has been shown to improve recovery in several residual disabilities after stroke. Approximately 35% of stroke survivors with early hemiparesis will not regain useful function and 20-25% of stroke survivors will be unable to walk without assistance (Hendricks et al., 2002).

A systematic review and meta-analysis included 58 studies which sought to determine the predictors of upper limb recovery after stroke (Coupar et al., 2012). Initial measures of upper limb neurological impairment and function were found to be the most significant predictors of upper limb recovery, with odds ratios [OR] of 14.84 (9.08–24.25) and 38.62 (8.40–177.53) respectively (Coupar et al., 2012).

Similar findings have been described in studies of recovery of language function after stroke. Studies report the greatest improvements in language occur in the first months after stroke (Cramer, 2008). However, a case-study has shown that the time span for recovery of language functions in global aphasia may be much longer. These studies show that recovery can continue for some time after the initial stroke occurs.

A meta-analysis investigated 19 different categories of interventions that have been shown to improve motor function after stroke (Langhorne et al., 2009). Upper limb functioning was shown to improve significantly using constraint-induced movement therapy, a form of physiotherapy where repetitive tasks are performed with the paretic limb, electromyography [EMG] biofeedback where electrodes are applied to the muscles to report electrical potentials to the patient via an auditory or visual means, mental imagery where physical functions are repeatedly mentally rehearsed, and robotics which allow high-intensity repetitive movements of the upper limb to be carried out (Langhorne et al., 2009). The authors concluded that most interventions involved elements of intensive, repetitive task-specific practice. This observation lends support to the belief that high-intensity repetitive task-specific practice might be the most effective principle when trying to promote motor recovery after stroke

(Langhorne et al., 2009). This study supports the idea that a repetitive task, such as walking, could help to improve outcomes after stroke by reducing disability and improving physical health.

A systematic review of 12 studies evaluated the relationship between increased physical activity after stroke and cognitive performance (Cumming et al., 2012).

Exercise interventions were heterogeneous; some studies compared different intensities of movement rehabilitation and others included a specific exercise programme (Cumming et al., 2012). Nine studies had sufficient data to be included in a meta-analysis, which indicated a significant benefit of intervention over control (Standardised mean difference [SMD] = 0.20, 95% CI: 0.04–0.36; $z = 2.43$, $p = 0.015$) (Cumming et al., 2012). The results provide evidence that increased physical activity after stroke can enhance cognitive performance.

1.5.3. Factors predicting recovery

In the acute phase of stroke, the strongest predictors of recovery (the return to as near pre-stroke functionality as possible) are stroke severity and patient age. Stroke severity is judged clinically, based upon the degree of neurologic impairment and the size and location of the infarction on neuroimaging with magnetic resonance imaging [MRI] or computed tomography [CT]. Other important influences on stroke recovery include ischaemic stroke mechanism, co-morbid conditions, epidemiologic factors and complications of stroke. In a prospective study that evaluated more than 1,100 patients from Denmark with acute stroke, those who had mild disability tended to recover within two months and those who had moderate disability recovered within three months (Jorgensen et al., 1995, Jorgensen et al., 1999). Recovery was

determined by using the Scandinavian Neurological Stroke Scale Score and Barthel Score (Mahoney and Barthel, 1965, Scandinavian Stroke Study Group, 1985). These scores were taken on a weekly basis until the end of rehabilitation and at 6 months post stroke (Jorgensen et al., 1995, Jorgensen et al., 1999). Patients with severe disability who recovered did so within four months, and those with the most severe disability within five months from onset. Functional recovery was preceded by neurologic recovery by two weeks on average (Jorgensen et al., 1995, Jorgensen et al., 1999). However, as mentioned in the preceding section, recovery (especially of language) can take many years.

Recovery from any disability is also an important behavioural outcome (Kaplan, 1990). Recovery involves improvement in both psychological factors (e.g. self-efficacy) as well as physical factors (Kaplan, 1990). Self-efficacy is an important determinant of how likely people are to act, to invest effort in and to persist when there are difficulties in a certain task (Bandura, 1977). In studies of stroke patients, self-efficacy predicts who will show the greatest improvements in mobility, controlling for actual severity of physical impairment (Johnston et al., 1999).

Understanding how physical impairments can influence psychological factors and similarly how psychological factors can influence physical impairments is essential to understanding the process of recovery after stroke.

1.6. Physical fitness and physical activity

Physical fitness is defined as “a set of attributes that people have or achieve that relates to the ability to perform physical activity” (Caspersen et al., 1985). Physical fitness is a set of attributes that are either health or skill related and can be measured

using specific tests (Caspersen et al., 1985). Physical fitness is often used synonymously with cardiorespiratory fitness and reflects the ability of a person to carry out moderate-to-high intensity exercise over a prolonged period of time. Maximum oxygen uptake ($\text{VO}_2 \text{ max}$) is a measurement of the maximum capacity of an individual to take up and use oxygen during incremental exercise. It is the gold standard method for determining an individual's cardiorespiratory fitness (Smith et al., 2012). Other important components of physical fitness include muscle strength and muscle power (Saunders et al., 2013). Muscle strength refers to the ability of a specific muscle or muscle group to exert force. Strength is associated with the ability to perform forceful movements such as pushing or lifting. Muscle power refers to the rate at which muscular work can be performed during a single explosive contraction. Power is associated with the ability to carry out dynamic forceful movements. In addition, other components of physical fitness can influence the ability to perform physical activities, including flexibility (range of motion about a specific joint), balance (ability to maintain stability and posture), and body composition (relative amounts of fat and fat-free mass) (Saunders et al., 2013).

Physical activity is defined as “any bodily movement produced by skeletal muscles that result in energy expenditure” (Caspersen et al., 1985). Physical activity can be categorised into occupational, sports, conditioning, household or leisure activities. Exercise is a subset of physical activity that is planned, structured and repetitive and has a final or intermediate objective i.e. the improvement or maintenance of physical fitness (Caspersen et al., 1985).

1.6.1. Benefits of physical activity

There is a linear association between physical activity and health, with those leading more physically active lives also leading healthier lives (Sallis, 2011). Physical activity reduces all-cause mortality by 33% (95% CI, 28–37%) in the general, physically active, population even after adjusting for other relevant risk factors such as age, hypertension, high cholesterol and obesity (Nocon et al., 2008). More recently a systematic review of 15 longitudinal studies with at least 5-year follow up and a total of 288,724 subjects aged between 18 and 85 years found that physical activity can have beneficial effects for weight gain and obesity, coronary heart disease [CHD] and type 2 diabetes the risk factors weight gain and obesity and the age-related diseases dementia and Alzheimer's disease (Reiner et al., 2013).

Similarly, a systematic review including 86 articles of physical activity (including both observational and intervention studies) in school aged children showed physical activity was associated with numerous health benefits including reduced obesity, improved bone health and improved blood pressure control (Janssen and Leblanc, 2010). Aerobic-based activities had the greatest health benefits, other than for bone health, in which case high-impact weight bearing activities were required (Janssen and Leblanc, 2010). Physical activity is a key determinant of energy expenditure and thus fundamental to energy balance and weight control.

In the general population those who are physically inactive are at a 20-30% increased risk of all-cause mortality compared to those who participate in at least 30 minutes of moderate intensity physical activity on most days of the week (WHO, 2012). Physical inactivity has been identified as the fourth leading risk factor for mortality globally (6% of deaths globally) (WHO, 2010). Studies suggest that

physical inactivity is a modifiable risk factor for not only stroke but also; cardiovascular disease, diabetes, hypertension, cancer, osteoarthritis and depression (Warburton et al., 2006). Low cardio-respiratory fitness accounts for about 16% of all deaths in both females and males than the other risk factors (Blair, 2009).

1.6.2. Physical fitness after stroke

Physical fitness is low after stroke (Saunders et al., 2013). Various factors can contribute to this reduced physical fitness. A main component of physical fitness, cardiorespiratory fitness, has been shown to be affected by stroke. Physical inactivity causes VO₂ max to decline irrespective of age and gender. Low VO₂ max is associated with reduced physical function and increased incidence of cardiovascular disease and recurrent cerebrovascular disease (Smith et al., 2012). A systematic review of 41 studies (n=1569) observed changes in oxygen uptake as a measure of aerobic fitness, and their associations with stroke severity (Smith et al., 2012). The review demonstrated that VO₂ max was substantially lower in the stroke survivors (around 26-87%) compared with age and gender matched healthy controls (Smith et al., 2012). Post-stroke physical inactivity is believed to further reduce the physical fitness of stroke patients.

1.6.3. Physical activity after stroke

Physical activity after stroke has been systematically reviewed both in the inpatient and community dwelling settings (West and Bernhardt, 2011, Field et al., 2013). With both of these studies demonstrating that physical activity is low post stroke (West and Bernhardt, 2011, Field et al., 2013). A systematic review of community

dwelling stroke survivors (26 studies recruiting 1,105 stroke survivors of which 11 studies were include in the meta-analysis) sought to determine how much physical activity is actually undertaken after stroke (Field et al., 2013). Physical activity was generally low in quantity, duration and intensity (Field et al., 2013). Poorer walking ability, specific sensorimotor functions and low mood were correlates of low physical activity (Field et al., 2013). However, establishing direction of causality is difficult since low mood could be both cause and consequence of low physical activity. Moreover, depression and low mood could negatively affect self-efficacy, motivation and self-determination which influence the uptake and maintenance of physical activity after stroke (Field et al., 2013, Nicholson et al., 2013). The meta-analysis generated an estimate of only 4355.2 steps per day (95% CI: 3210.4 to 5499.9) for community dwelling stroke survivors (Field et al., 2013). A systematic review of twenty six studies, involving 983 participants, found stroke survivors step counts were consistently reported at less than half of age-matched normative values (English et al., 2014).

Physical activity in an inpatient setting after stroke has also been systematically reviewed (West and Bernhardt, 2011). This systematic review included 24 studies and concluded the majority of the inpatient day was spent being inactive (median 48.1%, interquartile range [IQR] 39.6–69.3%), alone (median 53.7%, IQR 44.2–60.6%) and in their bedroom (median 56.5%, IQR 45.2–72.5%) (West and Bernhardt, 2011). Approximately one hour per day was spent in physiotherapy (median 63.2min, IQR 36.0–79.5) and occupational therapy (median 57.0 min, IQR 25.1–58.5). During these therapy sessions minimal time was spent in moderate to high physical activity (West and Bernhardt, 2011).

In addition to low physical activity, a longitudinal cohort study of acute stroke survivors who were followed for 1 year post stroke, found that stroke survivors spend on average 81% of their day sedentary (Tieges et al., 2015). Sedentary behaviour is any waking behaviour characterised by an energy expenditure ≤ 1.5 metabolic equivalents, while in a sitting, reclining or lying posture (Tremblay et al., 2017). Stroke survivors typically were more sedentary in the afternoon and evening (Tieges et al., 2015). This pattern of sedentary behaviour was independent of functional ability and did not change in the first year post stroke (Tieges et al., 2015). Increased sedentary time has negative implications on health even in people meeting physical activity guidelines (Wullems et al., 2016). Therefore, prolonged sedentary behaviour is likely to be detrimental to the cardiometabolic health of stroke survivors, as (Hamilton et al., 2007, Henson et al., 2013).

The results of these three studies indicate that physical activity in both inpatient and community settings, is low after stroke whilst sedentary behaviour is high. The impact of low physical activity and stroke outcome are discussed in the following section.

1.7. Associations between physical activity, physical fitness and stroke outcome

1.7.1. Physical activity and reducing recurrent stroke

There is currently a paucity of observational data about the relationship between physical activity after stroke and long-term outcome. Extrapolating the evidence that physical activity reduces the risk of a first ever stroke by about 27% (Lee et al., 2003), it seems likely that physical activity after stroke will reduce the risk of

recurrent stroke and other vascular events (Hackam and Spence, 2007) (Reimers et al., 2009).

Stroke and acute cardiac events have a higher incidence in patients with previous stroke than in the general population (Mol and Baker, 1991). However, more recent studies have shown that although recurrent stroke may be falling the high risk of stroke recurrence indicates the importance of employing therapies aimed at stroke recurrence (Dhamoon et al., 2006, Kernan et al., 2014). Although recurrent strokes account for approximately 30% of all strokes and the importance of physical activity after stroke is well documented, there is little long-term follow-up data available examining physical activity and recurrent events in stroke survivors (Thom et al., 2006). Risk modelling studies, based on data from primary prevention studies, have suggested that physical activity is likely to reduce the risk of recurrent stroke (Hackam and Spence, 2007). A preliminary study examining the effects of three different exercise interventions on cardiorespiratory fitness and coronary risk reduction in stroke survivors, found that 30 minutes of moderate-intensity aerobic exercise was more effective than 60 minutes of lower-intensity aerobic exercise or non-aerobic therapeutic exercise in reducing blood pressure and blood lipids levels (Rimmer et al., 2009). No other studies have examined the relationship between reducing recurrent stroke through physical activity in stroke survivors. Extrapolating the effects of physical activity on cardiovascular risk factor reduction and physical fitness in the non-stroke population indicates that regular exercise, delivered through stroke rehabilitation programmes, may reduce the risk of further events in stroke survivors (Gallanagh et al., 2011).

1.7.2. Physical activity and stroke outcome

There is accumulating evidence from observational studies that higher levels of physical activity prior to stroke is associated with better outcomes post stroke (Deplanque et al., 2006, Krarup et al., 2008, Stroud et al., 2009, Reimers et al., 2009, Deplanque et al., 2012). A systematic review sought to determine whether regular exercise (determined using self-assessment) can lower the risk of first-ever ischemic or haemorrhagic strokes (Reimers et al., 2009). This systematic review included 33 prospective cohort studies and 10 case-control studies and all the studies previously included in published meta-analyses (Lee et al., 2003, Wendel-Vos et al., 2004). In the meta-analysis of the 33 prospective cohort studies, risk of a fatal or non-fatal ischemic stroke was lowered by 24% in females and by 27% in males, while the risk of fatal or non-fatal cerebral haemorrhage was lowered by 8% in females and by 40% in males (Reimers et al., 2009). These results suggest that being physically active may reduce the risk of first ever stroke.

An observational study found stroke severity was inversely related to weekly self-reported exercise duration prior to stroke (no exercise: 36.1%; <2 hours: 49.3%; 2–5 hours: 58.8%; >5 hours: 64.0%; $P = 0.003$) (Deplanque et al., 2012). In terms of intensity, the beneficial effect of previous physical activity was observed in stroke survivors who did weak or moderate exercises. However heavy exercise may lead to adverse consequences (weak: 50.0%; moderate: 79.3%; heavy: 22.2%; $P < 0.0001$). Physical activity intensity was measured using a 14 point questionnaire adapted from the National Health Interview Survey of the National Centre for Health Statistics (Sacco et al., 1998). After adjustment for age, sex, arterial hypertension, diabetes, smoking, previous ischemic or congestive heart disease and peripheral arteriopathy, a

dose-dependent effect of physical activity duration (total per week) on the initial stroke severity was found. Therefore, physical activity prior to stroke may be a simple way to decrease cerebral ischemia severity (Deplanque et al., 2012).

1.7.3. Physical fitness training and stroke outcome

Low physical activity leads to low cardiorespiratory fitness after stroke (Saunders et al., 2013). There is convincing evidence from a meta-analysis of RCTs that physical fitness training after stroke, improves a range of clinically relevant outcomes (Saunders et al., 2013). This Cochrane Review included 45 trials involving 2,188 participants, which comprised cardiorespiratory (22 trials, 995 participants), resistance (eight trials, 275 participants), and mixed training interventions (15 trials, 918 participants). Cardiorespiratory training involving walking, improved maximum walking speed (mean difference [MD] 7.37 metres per minute, 95% CI 3.70 to 11.03), preferred gait speed (MD 4.63 metres per minute, 95% CI 1.84 to 7.43), walking capacity (MD 26.99 metres per six minutes, 95% CI 9.13 to 44.84), and Berg Balance scores (MD 3.14, 95% CI 0.56 to 5.73). Mixed training involving walking, increased preferred walking speed (MD 4.54 metres per minute, 95% CI 0.95 to 8.14), walking capacity (MD 41.60 metres per six minutes, 95% CI 25.25 to 57.95), and pooled balance scores but the evidence weaker (standardised mean difference [SMD] 0.26 95% CI 0.04 to, 0.49). Some mobility benefits also persisted at the end of follow-up. The authors concluded that the effects of physical fitness training on death, dependence and disability after stroke were unclear (Saunders et al., 2013). However, it was also concluded that there was sufficient evidence to incorporate cardiorespiratory and mixed training involving walking, within post-

stroke rehabilitation programmes to improve the speed and tolerance of walking and possibly balance (Saunders et al., 2013).

A recent systematic review and meta-analysis has highlighted that physical fitness training not only results in physical benefits but also psychological benefits (Eng and Reime, 2014). This systematic review included RCTs that evaluated the effect of structured exercise programs (e.g. functional, resistance, or aerobic training) on depressive symptoms (Eng and Reime, 2014). Thirteen studies (including 1022 stroke survivors) were included in the meta-analysis. Exercise (progressive resistance training; functional, aerobic, treadmill and Bobath exercises; individualised exercises with education; and community rehabilitation services) resulted in less depressive symptoms immediately after the exercise program ended, (SMD = -0.13 [95% CI = $-0.26, -0.01$], $I^2 = 6\%$, $p = 0.03$), however the review found these effects were not retained with longer term follow-up (SMD = -0.04 [95% CI = $-0.17, 0.09$], $I^2 = 1\%$, $p = 0.53$) (Eng and Reime, 2014). Follow-up was only measured in 10 of the 13 studies including 889 patients (Eng and Reime, 2014). Exercise appeared to have a positive effect on depressive symptoms across both the subacute (≤ 6 months post stroke) and chronic stage of recovery (> 6 months) (Eng and Reime, 2014). There was a significant effect of exercise on depressive symptoms when higher intensity studies were pooled, but not for lower intensity exercise protocols (Eng and Reime, 2014). Understanding that recovery from stroke can be both physical and psychological allows us to understand why there may be reasons that stroke survivors choose not to take part in physical activity. Although many stroke survivors appear physically well after their stroke i.e. no hemiparesis and able to mobilise independently, there may be psychological reasons to why they do not take part in physical activity (i.e. low

mood, depression, fear). Therefore, the challenges to increasing physical activity are discussed in the following section.

1.8. Challenges to increasing physical activity

Physical activity can be low in both stroke and non-stroke populations. To determine why low physical activity is so apparent, it is essential to understand what prevents and facilitates physical activity in all populations.

Perceived barriers and facilitators to any activity, health care intervention or drug can affect the likelihood of an individual undertaking a particular behaviour. The Scottish Household survey 2007/8 undertook a unique “Culture and Sport” module that saw over 6800 Scottish individuals aged 16 and over give more detail about their sports and cultural participation in the past 12 months (The Scottish Government, 2009). These participants reported the most common reasons for not participating in sport during the previous 12 months as poor health (54%), followed by a lack of interest (24%) and not having enough time (16%). Older respondents (aged 60 years and over) reported poor health as being the most common reason for not participating, while disinterest was the main reason for lack of participation in younger age groups (The Scottish Government, 2009). Similar results may be found for participation in other forms of physical activity.

A systematic review has been conducted to determine the perceptions of older adults (including some stroke survivors) on participation in physical activity (Franco et al., 2015). This systematic review included 132 qualitative studies involving 5,987 participants aged 60 years or older (Franco et al., 2015). The researchers identified

six major themes that may influence participation in physical activity by older adults.

These themes included:

1. Social influences (valuing interaction with peers, social awkwardness, encouragement from others, dependence on professional instruction);
2. Physical limitations (pain or discomfort, concerns about falling, comorbidities);
3. Competing priorities;
4. Access difficulties (environmental barriers, affordability);
5. Personal benefits of physical activity (strength, balance and flexibility, self-confidence, independence, improved health and mental well-being);
6. Motivation and beliefs (apathy, irrelevance and inefficacy, maintaining habits) (Franco et al., 2015).

Tackling these themes may increase physical activity in older adults and also stroke survivors.

1.8.1. Challenges to physical activity after stroke

Although an increasing body of evidence demonstrates that exercise training after stroke is effective, most improvements gained tend to be lost at long-term follow-up (Brazzelli et al., 2011). Long-term engagement in physical activity after stroke is being recommended to maintain the improvements gained from rehabilitation (Brazzelli et al., 2011). However, research has identified that the majority of stroke survivors return to a sedentary life after rehabilitation and do not meet the daily recommended physical activity levels (Shaughnessy et al., 2006, Rand et al., 2009, Field et al., 2013). It is necessary to explore why this is particularly apparent after

stroke. Perceived barriers and facilitators to physical activity after stroke may, in theory, differ considerably from the barriers and facilitators perceived by the general population and other patient groups. These differences may be due to the multiple long-term effects of stroke such as residual neurological deficits, psychological problems and fatigue. Few studies have sought to determine what prevents some stroke survivors from being physically active. One structured literature review investigated psychological and social factors that may influence physical activity engagement after stroke (Morris et al., 2012). Twenty studies from 19 publications (9 surveys, one RCT and 10 qualitative studies) were included. Seventeen studies reported findings relevant to psychological factors and fourteen reported findings relevant to social factors. Self-efficacy, physical activity beliefs and social support were relevant to physical activity behaviour after stroke (Morris et al., 2012). This review focussed only on the psychological and social factors influencing physical activity uptake and not all barriers and facilitators such as environmental factors associated with physical activity post stroke. It is important to understand all the barriers to physical activity perceived by stroke survivors since this will enable targeted behaviour change interventions to enable stroke survivors to engage in and increase their physical activity.

1.9. Behaviour change

A behaviour is anything a person does in response to internal or external events. Behaviours are controlled by the brain and carried out by the body. The behaviour of individuals, communities and populations is one of the major determinants of their health outcomes. Different patterns of behaviour are deeply embedded within

individual social, physical and cultural contexts (NICE, 2007). To tackle global causes of mortality and morbidity, it may be necessary to change these embedded behaviours. In all populations changing embedded health behaviours can be achieved through the development of appropriately targeted behaviour change interventions (NICE, 2007).

“A behaviour change intervention is a complex intervention with a number of interacting components and behaviours” (Craig et al., 2008). Behaviour change interventions have also been described as “co-ordinated sets of activities designed to change specified behaviour patterns” (Michie et al., 2011). In general, these behaviour patterns are measured in terms of the prevalence or incidence of particular behaviours in specified populations. Interventions are used to promote uptake and optimal use of effective clinical services, and to promote healthy lifestyles (Michie et al., 2011). These interventions can occur at individual, community and population level. Development and evaluation of behaviour change interventions requires a good understanding of how the intervention can cause a change in behaviour. A lack of effect may reflect implementation failure rather than genuine ineffectiveness (Campbell et al., 2000). Therefore, a thorough process of evaluation is necessary to identify implementation problems either during or after a trial has been conducted (Campbell et al., 2000). If an intervention is successful it can be used to guide healthcare providers to implement what is considered to be best practice (for example (Cochrane Reviews, NICE guidance)) (Michie et al., 2011).

Interventions to change behaviour have the potential to alter current patterns of disease. A genetic predisposition to a certain disease cannot be changed and social circumstances may be difficult to alter, however, an individual's behaviour may be easier to change. Nevertheless, many previous attempts to change individuals' health related behaviours have been unsuccessful. Often this is because behaviour change interventions have failed to take into account the theories and principles of successful planning, delivery and evaluation (NICE, 2007).

1.10. Theory to aid behaviour change intervention development

A theory is a fact-based framework for describing a phenomenon. In psychology, theories are used to provide a model for understanding human thoughts, emotions, and behaviours (Cherry, 2014). Theories tend to have two key components i) a behaviour must be described and ii) the theory must make predictions about future behaviour (Cherry, 2014). There are three main reasons for promoting the use of theory in designing behaviour change interventions (Michie et al., 2008):

1. Interventions are likely to be more effective if they target causal determinants of behaviour and behaviour change.
2. Theory can be tested and developed by evaluations of interventions only if those interventions and evaluations are theoretically informed.
3. Theory-based interventions facilitate an understanding of what works and thus are a basis for developing better theory across different contexts, populations, and behaviours (Michie et al., 2008).

1.10.1. The MRC Framework for developing and evaluating complex interventions

In 2000, the Medical Research Council [MRC] published a Framework for the Development and Evaluation of RCTs for Complex Interventions to Improve Health, to help researchers recognise and adopt appropriate methods when developing and evaluating complex interventions (MRC, 2000). The framework, based on theory, uses a phased approach to the development and evaluation of complex interventions (MRC, 2000). The Framework has since been updated to take a less linear approach and indicates the many interaction between the phases of intervention development (Craig et al., 2008). Key elements of the framework are detailed in figure 1. The key elements of the framework were used as the basis for the development of the behaviour change intervention, which is described in chapter 7.

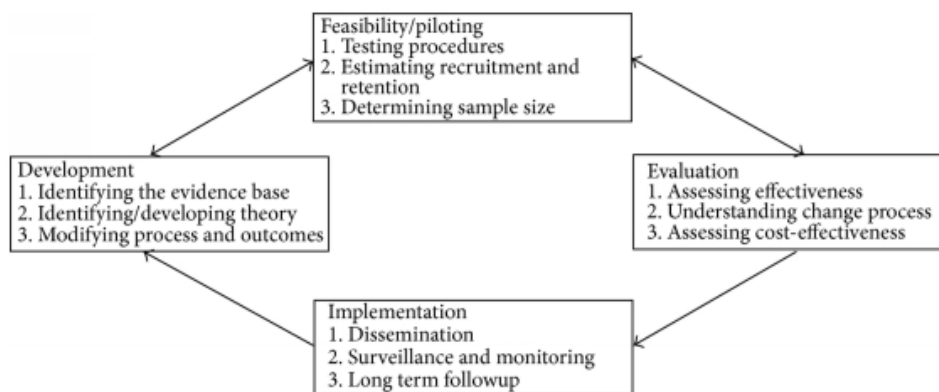


Figure 1: Key elements of the development and evaluation process of the MRC framework

Flow diagram of MRC framework taken from (Craig et al., 2008)

1.10.2. The Theoretical Domains Framework [TDF]

To develop a behaviour change intervention to increase physical activity after stroke it was necessary to carry out preliminary research to identify reasons why stroke survivors are not physically active. To be able to successfully analyse all of these data, and use the findings to decide the key components of the behaviour change intervention, careful consideration of the necessary theory was required. Therefore it was considered necessary to use a behaviour change model to analyse the data generated from this PhD. The TDF was developed in 2005 with the aim to simplify and combine a vast array of behaviour change theories (Michie et al., 2005). It was recognised, by the authors of the TDF, that clarification and simplification of the plethora of psychological theories was necessary to maximise their accessibility and usefulness (Michie et al., 2005). The TDF authors identified and synthesised 33 theories and 128 key theoretical constructs related to behaviour change into a single framework. This process was done to assess implementation and other behavioural problems, to inform intervention design. The TDF covers a comprehensive range of scientific explanations for behaviour and behaviour change (Michie et al., 2005). The advantage of using an integrative theoretical framework, such as the TDF, over a single theory of health behaviour, is that it encompasses multiple explanatory domains and therefore provides a more comprehensive assessment of factors which are important to the stroke population (Michie et al., 2011). To develop the TDF a six stage consensus approach was used:

1. Identifying theories and theoretical constructs relevant to behaviour change
2. Simplifying these resulting constructs into overarching theoretical domains based on their commonalities
3. Evaluating the importance of the theoretical domains
4. Conducting an interdisciplinary evaluation and synthesis of the domains and constructs
5. Validating the domain list
6. Piloting interview questions relevant to the constructs and domains (Michie et al., 2005).

Therefore the *original* TDF comprised of 12 domains derived from the 128 different theoretical constructs of theory-based explanations for behaviour. The domains included; ‘knowledge’, ‘skills’, ‘social role and identity’, ‘beliefs about capabilities’, ‘beliefs about consequences’, ‘motivation and goals’, ‘nature of the behaviour’, ‘environmental context and resources’, ‘social influences’, ‘social identity’, ‘emotion’ and ‘behaviour regulation’ [figure two].

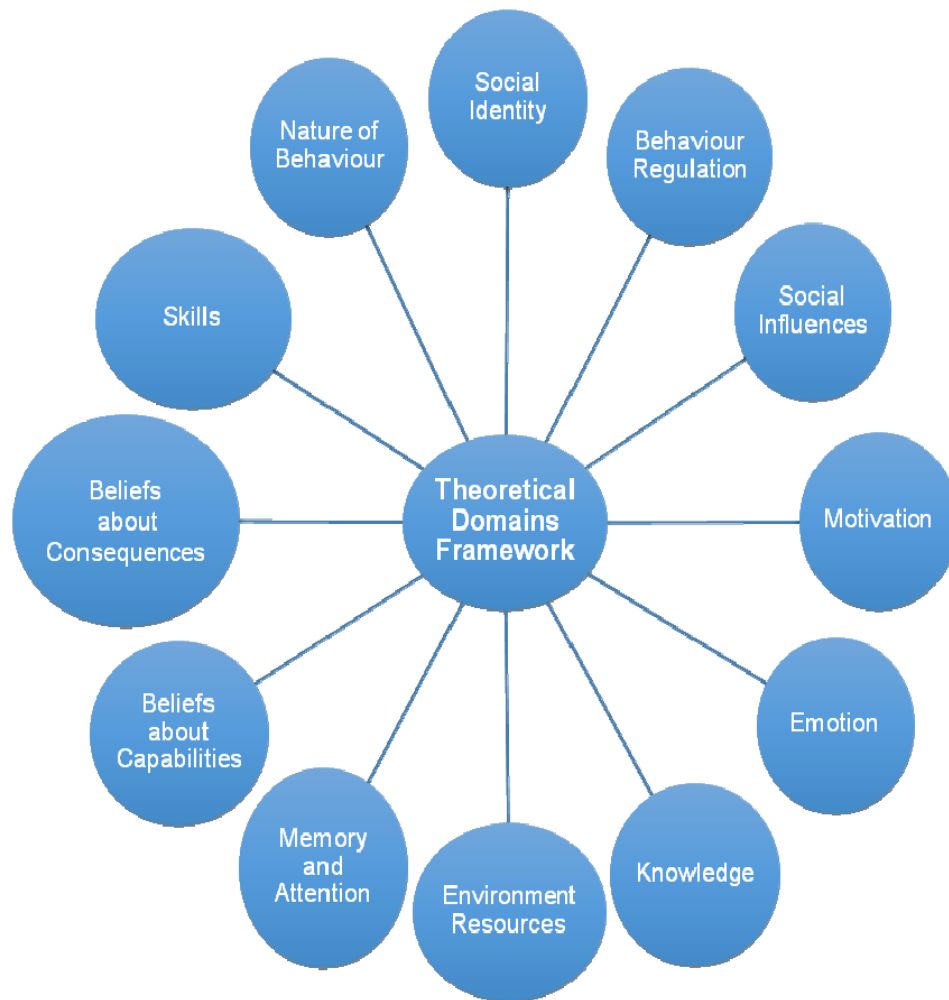


Figure 2: The Theoretical Domains Framework

The domains of the Theoretical Domains Framework (Michie et al., 2005)

It should be noted that the TDF was updated in 2012 (Cane et al., 2012). A validation study including 112 theoretical constructs was examined by 37 experts in the field of behaviour change. This validation study increased the theoretical domains from 12 to 14, removing the original domains of “nature of behaviour”, “knowledge” and “motivation” and including “goals”, “intention”, “reinforcement” and “optimism”.

However, due to work already being undertaken with the original framework, the original 2005 framework was used throughout this PhD thesis.

The authors of the TDF then sought to map theoretically derived domains to specific behaviour change techniques [BCTs] (Michie et al., 2008). The authors acknowledged a BCT is defined “as an active component of an intervention designed to change behaviour” (Michie et al., 2014). The defining characteristics of a BCT are that it is “observable, replicable, irreducible and a component of an intervention design to change behaviour and a postulated active ingredient within the intervention” (Michie et al., 2014). The researchers sought to determine which BCTs could be used to target behaviour domains when developing behaviour change interventions (Michie et al., 2008). They acknowledged that there is a vast expanse of determinants of behaviour change, and trying to determine suitable BCTs for every determinant would prove challenging. Therefore, a summary document was generated incorporating both the determinants of behaviour change from the TDF and previously published determinants (Fishbein et al., 2001). Therefore only 11/12 TDF domains were included in the mapping of BCTs. To do this, a list of behaviour change techniques and definitions was generated from techniques published in two systematic reviews, supplemented by “brainstorming” and a systematic search of nine applied psychology textbooks (Michie et al., 2008). Interrater reliability of extracting the techniques and definitions from the textbooks was assessed. Four experts judged which techniques would be effective in the theoretical constructs associated with the TDF (Michie et al., 2008). The behavioural domains and relevant BCTs are shown in table one. The red boxes indicate where consensus between the four expert judges was reached, and these behaviour change techniques are deemed

appropriate for altering the construct domain. The behaviour change techniques that are not deemed appropriate to alter the construct domain are left blank. This preliminary work demonstrated the possibility of developing a comprehensive, reliable taxonomy of techniques linked to theory and this taxonomy, along with the TDF, was used to choose the most appropriate techniques for the behaviour change intervention (see chapter seven, section 7.3).

Table 1: Map of the theoretically derived domains to behaviour change techniques

Technique for behaviour change	Techniques deemed to be effective in changing each construct domain										
	1	2	3	4	5	6	7	8	9	10	11
Goal/target specified: behaviour or outcome											
Monitoring											
Self-monitoring											
Contract											
Rewards; incentives (self-evaluation)											
Graded tasks, starting with easy tasks											
Increasing skills: problem-solving, decision-making, goal-setting											
Stress management											
Coping skills											
Rehearsal of relevant skills											
Role-play											
Planning, implementation											
Prompts, triggers, cues											
Environmental changes (eg objects to facilitate behaviour)											
Social processes of encouragement, pressure, support											
Persuasive communication											
Information regarding behaviour, outcome											
Personalised message											
Modelling/ demonstration of behaviour by others											
Homework											

Personal experiments, data collection (other than self-monitoring)												
Experiential; tasks to gain experiences to change motivation												
Feedback												
Self-talk												
Use of imagery												
Perform behaviour in different settings												
Shaping of behaviour												
Motivational interviewing												
Relapse prevention												
Cognitive restructuring												
Relaxation												
Desensitisation												
Problem-solving												
Time management												
Identify prepare for difficult situation												

Key:

Techniques judged to be effective in changing each construct domain	
1	Social/ professional role and identity
2	Knowledge
3	Skills
4	Beliefs about capabilities
5	Beliefs about consequences
6	Motivation and goals
7	Memory, attention, decision processes
8	Environmental context and resources
9	Social influences
10	Emotion
11	Action Planning

1.11. Behaviour change to increase physical activity

Many behaviour change interventions focus on changing intention (the planning to perform a specific behaviour) and self-efficacy (the belief that one can successfully perform the specific behaviours necessary to achieve an outcome such as walking a specific distance) (Bandura, 1977). These interventions typically encompass information based material and cognitive and/or behavioural strategies designed to increase participants' knowledge, self-efficacy and use of self-management behaviours (Barlow et al., 2002, Sawyer and Aroni, 2005).

Systematic reviews of behaviour change interventions aimed at increasing physical activity have been previously conducted (Lau et al., 2011, Orrow et al., 2012). A systematic review of 15 trials (n=8,745) was conducted to determine whether physical activity promotion based in primary care had sustained effects on physical activity or fitness in sedentary adults (Orrow et al., 2012). In 13 trials presenting self-reported physical activity, there were small to medium positive intervention effects at 12 months after completion of the intervention (OR 1.42, 95% CI 1.17 to 1.73; SMD 0.25, 0.11 to 0.38) (Orrow et al., 2012). A systematic review including nine randomised controlled trials sought to evaluate the efficacy and methodological quality of information and communication technology based physical activity interventions for children and adolescents (Lau et al., 2011). Information and communication technologies are devices such as the internet and mobile phones which are used to disseminate information. Of the nine studies, seven demonstrated positive and significant within-group differences in at least one psychosocial or behavioural physical activity outcome. In total, three studies reported positive and significant between-group differences favouring the information and communication

group. When between-group differences were compared across studies, effect sizes were small in six studies and large in three studies (Lau et al., 2011). Although data are limited this review provides evidence supporting the positive effects of information and communication technologies in increasing physical activity. Evidence suggests that behaviour change interventions can be used to successfully increase physical activity, but their implementation and tailoring to the target population is essential.

1.12. Behaviour change after stroke

It is often hypothesised that improving a patient's understanding of their condition and its treatments will increase their engagement in a recommended behaviour (Kaplan, 1990). However, a pilot RCT found repeated encouragement and verbal instruction ineffective in increasing physical activity post stroke (Boysen et al., 2009). Therefore, different approaches to increasing physical activity in stroke survivors are required.

Behaviour change interventions have previously been undertaken in stroke. These interventions have attempted to increase stroke survivors' perceived control of their recovery. A randomised controlled trial was conducted to examine the effects of a self-management workbook intervention designed for use with individuals after first-ever stroke (Jones et al., 2009). The individualised self-management workbook was based on self-efficacy principles; incorporating sections to increase mastery, vicarious experience and feedback (Jones et al., 2009). Seven men and three women, with a mean age of 61.5 years (standard deviation [SD] =8.15), on average 24.2 weeks (SD =18.29) following first stroke, all with residual restriction of activity and

participation were included in the study. A randomisation test indicated a statistically significant change in Stroke Self-Efficacy Questionnaire scores and Recovery Locus of Control Scale scores following the introduction of the workbook (Jones et al., 2009). This study shows preliminary evidence that the use of an individualised stroke self-management intervention is acceptable and can lead to a change in self-efficacy in stroke survivors (Jones et al., 2009). This workbook also contained goal setting elements including target setting to allow participant to choose small, personal and manageable targets, to help them achieve their overall goals (Jones et al., 2009).

A second behaviour change intervention with stroke survivors gave participants a workbook designed to increase control beliefs. The workbook drew on cognitive behavioural therapy techniques by including activities designed to allow the participant to attain the coping skills to encourage self-management after stroke. These coping skills provided participants with information about stroke and recovery, guidance on coping skills and self-management instruction (Johnston et al., 2007). The workbook was tested as part of a randomised controlled trial and led to significantly improved recovery from disability, allowing for initial disability, compared to control group and helped the stroke survivors increase their perceived control over their recovery (Johnston et al., 2007). At discharge, stroke survivors were randomly allocated (with their carers) to a five week intervention (n=103) or control (normal care: n=100). The main outcome was recovery from disability using a performance measure, with distress and satisfaction as additional outcomes. The first intervention contact was a home visit where the workbook was given to the participants, who were instructed on its use. At the second contact (a home visit the

following week), the implementer answered questions, provided encouragement, and offered more information about stroke risk factors. The third and fourth contacts were by telephone at weekly intervals. During these contacts, the implementer monitored goals and achievements, and continued to provide encouragement. The last contact was a home visit during the fifth week of the intervention period, when the numbers of completed quizzes and tasks, diary days and set goals, were recorded. The intervention group showed significantly better disability recovery, allowing for initial levels of disability, than those in the control group, $F(1,201)=5.61$, $p=0.019$ (Johnston et al., 2007). A prospective cohort study within this randomised controlled trial of stroke survivors tested this behaviour change workbook and showed the importance of perceived behavioural control in increasing physical activity post-stroke (Johnston et al., 2007, Bonetti and Johnston, 2008). The cohort study showed walking limitations and walking recovery after stroke was predicted by stroke survivors' perceived behaviour control (Bonetti and Johnston, 2008).

1.12.1. Development of a behaviour change intervention to increase physical activity after stroke

Two key aspects of behaviour change that appeared imperative in previous behaviour change interventions to increase physical activity after stroke were: feedback (1) and goal setting (2).

- (1) Knowledge is often assumed as a necessity in promoting behavioural change as demonstrated by previous literature. Health knowledge, or education, refers to the knowledge and understanding people have about health-related issues. It is important that people understand the causes of ill-health and

recognise the extent to which they are vulnerable to, or at risk from, a health threat. In other words, knowledge is a key component of behaviour change, but on its own it is not sufficient to bring about behaviour change (Boysen et al., 2009). It is believed knowledge promotes awareness of personal risk behaviour implying that people will only consider changing their behaviour when they become aware that they are potentially putting their health at risk (i.e., suffering a life changing event such as a stroke). Feedback has been shown to increase both awareness of health behaviour and intentions to change that behaviour (Brug et al., 1999, Proper et al., 2003, Watkinson et al., 2010). Feedback and monitoring have also been shown to be one of the key proven components of behaviour change interventions as highlighted in the NICE guidelines (NICE, 2014). Therefore, a form of feedback was considered to be an essential component of the proposed behaviour change intervention. Feedback on physical activity can take many forms such as an accelerometer, pedometer or self-reported measure. The method of feedback and the rationale behind its choice is discussed in chapter seven.

- (2) In rehabilitation, goal setting is used for a number of reasons, such as to improve patient outcome; to provide motivation to the patient; to make sure all team members are working towards the same thing; and finally, to monitor the effectiveness of the rehabilitation process (Wade, 2009). As discussed earlier in this chapter, previous studies have developed theory-based workbook interventions for people recovering from stroke which also include setting goals as a key component (Jones et al., 2009) (Johnston et al., 2007). As the aim of goal setting is a change in patient behaviour (e.g. increasing

physical activity) theories of behaviour and behaviour change have the potential to guide the development of goal-setting interventions. A systematic review identified three theories of behaviour change that may be useful to goal setting interventions (Scobbie et al., 2009). One of these behaviour change theories was Social Cognitive Theory (Bandura, 1989). A key component of Social Cognitive Theory is the importance of self-efficacy, which has previously been demonstrated as a key component of increasing physical activity after stroke (Johnston et al., 2007). Therefore, both goal-setting and self-efficacy need to be taken into account when developing the behaviour change intervention. Furthermore, a systematic review of the effects and experiences of goal setting after stroke found that although the principles of goal setting after stroke are deemed as best practice in aiding recovery after stroke, there is actually little evidence demonstrating the feasibility of goal setting in stroke rehabilitation (Sugavanam et al., 2013). Therefore, the use of goals setting in our behaviour change intervention would help to determine its feasibility and acceptability after stroke.

1.13. Conclusion

The aim of this introductory chapter was to detail the background and rationale for this programme of work and PhD thesis.

- Stroke is a debilitating condition that can leave survivors with many life-long disabilities
- Stroke can lead to a reduction in physical activity, with long-term maintenance of physical activity low

- There are potentially several barriers to the uptake and/or maintenance of physical activity after stroke
- Behavioural change intervention may help to increase physical activity after stroke
- Theory is key to the development of behaviour change interventions
- The TDF will aid the development of behaviour change intervention
- The overall aims of this programme of work and the aims of the individual studies are presented in the following chapter (chapter 2).

CHAPTER 2 Aims

2.1. Overall aim of thesis

Physical activity after stroke is low and an increase in physical activity after stroke may reduce disability. Secondary benefits of increasing physical activity may include increasing energy, lowering blood pressure and lowering both HDL and LDL cholesterol. These benefits may in turn reduce further disability from the stroke, reduce the risk of secondary strokes and help to control body weight and physical fitness. Behaviour change interventions have been shown to help change behaviour and improve health in many patient groups including stroke. Therefore, it is plausible that a behaviour change intervention to increase physical activity can be beneficial to stroke survivors.

Therefore the overall aim of this work was to develop and test a behavioural change intervention to increase physical activity, predominantly through walking, after stroke.

It was decided to target walking rather than other modes of physical activity. Walking is the simplest mode of physical activity, requiring no other equipment such as a bike or a swimming pool, to be undertaken. Walking is cheap, easy to undertake and can be done in most locations. However, by including walking as the component of physical activity, the study would be limited to only ambulatory stroke survivors. Although a drawback to the study, it was felt this would be the safest way to carry out a simple, home-based behaviour change intervention for stroke survivors. Increasing steps taken would be the targeted walking behaviour.

In order to address the above aim, six interlinking studies were undertaken. The aims and objectives of each of these studies and their link to the overarching aim are detailed in the following sections.

2.2. Study one

The first step in developing a behaviour change intervention is to review the current literature and evidence in the study area (Craig et al., 2008).

A systematic review is regarded as the strongest form of evidence as it applies strategies that limit bias in the selection, critical appraisal and assembly of data (Burns et al., 2011). Therefore, a systematic review was conducted as the first study for this programme of work, with the following aim:

To evaluate, critically appraise and synthesise the data on the perceived barriers and facilitators to physical activity after stroke.

This systematic review of perceived barriers and facilitators to physical activity after stroke is discussed in chapter three of this thesis.

2.3. Study two

The systematic review concluded there were few studies investigating the perceived barriers and facilitators to physical activity after stroke, and that the already published studies potentially had limited generalisability to the UK stroke population. It was therefore judged to be appropriate to conduct our own qualitative study to examine the perceived barriers and facilitators to the local stroke population in Edinburgh. A qualitative interview study was chosen to do this as it would provide descriptive data from real-time stroke survivors within the local community.

Therefore, a qualitative interview study was conducted as the second study of this programme of work, with the following aim:

To qualitatively explore stroke survivors' perceived barriers and facilitators to physical activity after stroke.

This qualitative interview study is discussed in chapter four of this thesis.

2.4. Study three

Both the systematic review and the qualitative study highlighted the influence of self-efficacy in increasing physical activity. Evidence suggests that the extent of self-efficacy towards walking after stroke can be a long term predictor of physical activity (Bonetti and Johnston, 2008). Earlier work conducted prior to this PhD (Carroll et al., 2012), generated previously unanalysed data on barriers and facilitators to physical activity after stroke. These quantitative data encompassed specific questions exploring self-efficacy and intention to physical activity post stroke. In light of the evidence from both the systematic review and qualitative study it was perceived to be helpful to analyse these data to inform the development of the behaviour change intervention.

Therefore, a quantitative study was conducted as the third study of this programme of work, with the following aims:

- (i) To explore stroke survivors perceived barriers and facilitators to physical activity after stroke.
- (ii) To explore stroke survivors perceived self-efficacy and intervention to increasing physical activity after stroke.

This quantitative study is discussed in chapter five of this thesis.

2.5. Study four

As discussed in section 1.12.1, it was envisaged that the behaviour change intervention would incorporate a feedback device, so participants could clearly see how much physical activity they were undertaking on a daily basis. It was envisaged this would be done using a pedometer (see chapter seven). An opportunity arose to collaborate with a team at Newcastle University who had developed an accelerometer which incorporated an immediate feedback screen (similar to that of a pedometer). This collaboration was seen as an exciting opportunity to be able to help develop an accurate physical activity monitor for use with stroke survivors, which would not only accurately record the wearer's step count but visually provide this information on a screen to the wearer. Therefore, a device development study was conducted as the fourth study of this programme of work, with the following aim:

To validate a newly developed accelerometer with stroke survivors.

This device development study is discussed in chapter six of this thesis.

Data gathered from studies one-four were used in the development of the behaviour change intervention (see figure 3). This development process is discussed in chapter seven of this thesis.

2.6. Amalgamation of first four studies

Chapter seven details the amalgamation of the first four studies that are incorporated to develop the behaviour change intervention. To develop the behaviour change intervention it was essential to understand psychological theory and how theory plays a key role in behaviour and behaviour change. Understanding psychological theory

and applying this to the results from the systematic review, qualitative and quantitative studies allowed the determination of the most appropriate behaviour change techniques for inclusion in the behaviour change intervention. The intervention booklet was developed along with other key components of the behaviour change intervention.

2.7. Study Five

Once the behaviour change intervention had been developed the next stage was to test the intervention with a sample of stroke survivors. As this was a newly developed behaviour change intervention, it was essential to determine if all aspects of the intervention were easily followed and understood by stroke survivors. A before and after study investigating the feasibility and acceptability of the intervention was developed. Therefore, an uncontrolled pilot study was conducted as the fifth study of this programme of work, with the following aim:

To examine the feasibility and acceptability of the behaviour change intervention with stroke survivors.

The uncontrolled pilot study is discussed in chapter eight of this thesis

2.8. Study Six

Having previously attempted to test the developed behaviour change intervention's feasibility and acceptability with stroke survivors (chapter eight) amendments to the protocol were required. These amendments were needed to improve recruitment to the study by targeting a wider range of stroke survivors who were interested in taking part in the intervention. Two key changes were made to the behaviour change

intervention protocol. Therefore, a second uncontrolled pilot study was conducted as the sixth study of this programme of work, with the following aim:

To examine the feasibility and acceptability of the amended behaviour change intervention with stroke survivors.

The second uncontrolled pilot study is discussed in chapter eight of this thesis.

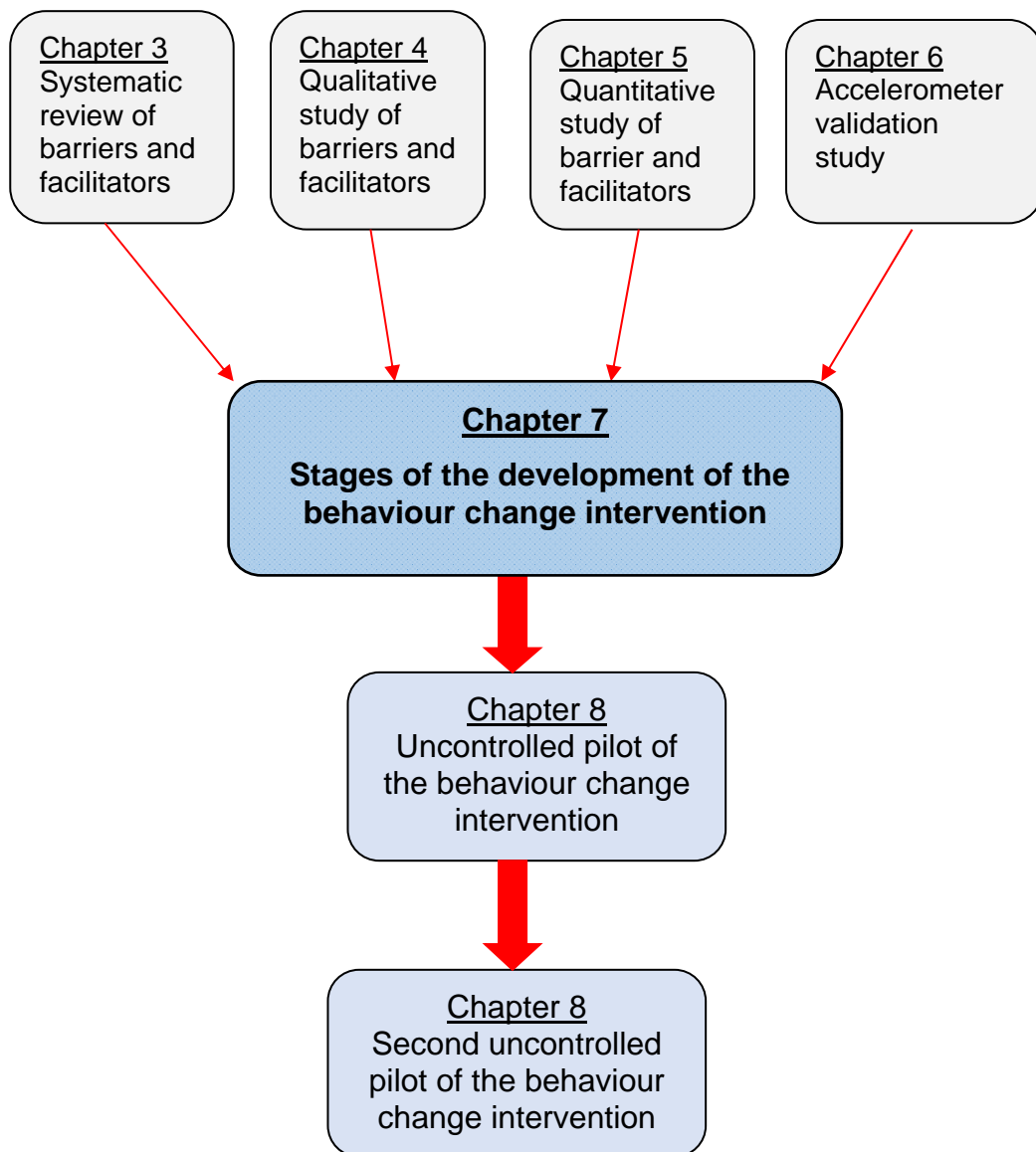


Figure 3: Flow diagram of the interlinking studies

CHAPTER 3 A systematic review of the perceived barriers and facilitators to physical activity after stroke

3.1. Introduction

The next three chapters seek to determine the barriers and facilitators to physical activity perceived by stroke survivors, using three different approaches (systematic review, qualitative and quantitative data analysis). A systematic review of the literature on the perceived barriers and facilitators to physical activity after stroke was undertaken as study one of this PhD, and is presented in this chapter. This study has been published in the journal 'International Journal of Stroke' (Nicholson et al., 2013). All the literature searches, data extraction and drafting of the manuscript was carried out by SN. The search strategies were developed with the help of the University of Edinburgh library staff and the MEDLINE search strategy can be found in appendix 1. GM and CG also helped with screening of potential articles and all of the authors provided comments and edited the final draft prior to publication. The search strategy

3.2. Background

Physical activity is reduced after stroke which may contribute to disability from the primary stroke and increase the likelihood of secondary strokes. Using the MRC framework, the first step in the development of a complex intervention is to use the available evidence and theory effectively. The MRC recommends that a systematic review should be undertaken in the relevant field if there are no recent high quality systematic reviews (Craig et al., 2008). A systematic review is regarded as the strongest form of evidence as it applies strategies that limit bias in the selection,

critical appraisal and assembly of data (Burns et al., 2011). Therefore, it was felt a systematic review would be an appropriate way to elicit a wide and descriptive analysis of the available literature on barriers and facilitators to physical activity perceived by stroke survivors.

Systematic review

A systematic review of perceived barriers and motivators to physical activity after stroke

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Background and purpose Physical fitness is impaired after stroke, may contribute to disability, yet is amenable to improvement through regular physical activity. To facilitate uptake and maintenance of physical activity, it is essential to understand stroke survivors' perceived barriers and motivators. Therefore, we undertook a systematic review of perceived barriers and motivators to physical activity after stroke.

Methods Electronic searches of EMBASE, Medline, CINAHL, and PsychInfo were performed. We included peer-reviewed journal articles, in English, between 1 January 1966 and 30 August 2010 reporting stroke survivors' perceived barriers and motivators to physical activity.

Results Searches identified 73 807 citations of which 57 full articles were retrieved. Six articles were included, providing data on 174 stroke survivors (range 10 to 83 per article). Two reported barriers and motivators, two reported only motivators, and two reported only barriers. Five were qualitative articles and one was quantitative. The most commonly reported barriers were lack of motivation, environmental factors (e.g. transport), health concerns, and stroke impairments. The most commonly reported motivators were social support and the need to be able to perform daily tasks.

Conclusion This review has furthered our understanding of the perceived barriers and motivators to physical activity

after a stroke. This review will enable the development of tailored interventions to target barriers, while building upon perceived motivators to increase and maintain stroke survivors' physical activity.

Key words: barriers, motivators, physical activity, rehabilitation, stroke, therapy

Introduction

Globally, stroke affects 16 million individuals every year. While mortality rates from stroke have fallen in recent years, the prevalence of disability following stroke remains high (1). After stroke, physical activity (2,3) and physical fitness (4) are low. This could contribute to further activity limitations and increased disability (4).

There is accumulating evidence that higher levels of physical activity prior to stroke are associated with better outcomes (5–8). However, there is currently a paucity of observational data relating physical activity after stroke to stroke prognosis. Extrapolating the evidence that physical activity reduces the risk of a first-ever stroke by 27% (9) suggests that physical activity after stroke may reduce the risk of recurrent stroke and other vascular events (10). Furthermore, there is convincing evidence from a meta-analysis of randomized controlled trials (RCTs) that physical fitness training (a subset of physical activity) after stroke improves outcome, i.e. reduced dependence on others during ambulation, improved walking speed, and tolerance (11). In addition, it is highly likely that stroke survivors need to maintain physical activity in order to maintain the benefits of a course of physical fitness training (12). This evidence is now being implemented into clinical practice with the development of community exercise after stroke services (13). Therefore, while there is a clear argument that stroke survivors should be encouraged to increase their physical activity, the best way to do this is unclear.

Although physical fitness training has been shown as beneficial post-stroke (11), not all stroke survivors wish to participate in physical fitness training (12). Therefore, approaches to facilitate uptake and long-term maintenance of physical activity after stroke need to be developed (14). If we are to encourage as many stroke survivors as possible to participate in exercise services, it is crucial that we understand the barriers and motivators to physical activity after stroke.

Perceived barriers and motivators to any health behaviour (e.g. physical activity), healthcare intervention, or drug can

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Conflicts of interest: None declared.

DOI: 10.1111/j.1747-4949.2012.00880.x

greatly influence the likelihood of an individual's uptake of that particular behaviour (15). In the 2003 Scottish Government report 'Sport, Exercise and Physical Activity: Public Participation, Barriers and Attitudes', the most commonly cited reasons for being inactive for the general population were a lack of time, poor health, motivational reasons, and the accessibility and availability of facilities (16). Health education is considered to be essential to promote health and prevent disease in the general population. Helping people develop confidence to act on health education is best achieved through personal forms of communication, and through community outreach programs (17). However, a recent multi-centre trial in stroke survivors examining the effects of repeated encouragement and verbal instruction was not effective in increasing physical activity (18). Therefore, perceived barriers and motivators to physical activity after stroke may differ considerably from those perceived by the general population because of the multiple long-term effects of stroke, e.g. residual neurological deficits, psychological problems, and fatigue. A better understanding of the nature of these perceived barriers and motivators could help healthcare professionals become more effective in motivating stroke survivors to become more physically active.

A recent review examined the psychological and social factors that influence the uptake and maintenance of physical activity after stroke (19). The review found that self-efficacy, physical activity beliefs, and social support appeared to be particularly relevant to physical activity behaviour (19). However, the review focussed only on psychological and social factors and not on physical or environmental factors that influence physical activity uptake. For example, environmental barriers such as lack of transport may be important to stroke survivors who, as a consequence of their stroke, are unable to drive. Furthermore, the review included five studies where stroke survivors' data were interspersed with participants with other conditions (e.g. multiple sclerosis, joint and connective tissue disease, and spinal cord injury), which may have influenced interpretation of the results (19).

The aim of the present study was to systematically review the literature to identify all studies examining perceived barriers and motivators to physical activity after stroke, with the specific objectives to (i) identify the most commonly reported barriers and motivators to physical activity after stroke and (ii) identify any tools/questionnaires specifically designed to explore perceived barriers and motivators to physical activity after stroke.

Methods

Review definitions

Physical activity was defined as any bodily movement produced by the contraction of skeletal muscle that increases energy expenditure (20).

Perceived barriers were defined as perceived obstacles to engaging in behaviour which might otherwise help prevent disease and enhance health (i.e. physical activity) (20). Per-

ceived barriers may reflect environmental factors (external barriers) such as lack of support from friends and family, low resources, or a lack of time due to other responsibilities. Additionally, perceived barriers may represent more individual, psychologically based factors (personal barriers) such as a lack of motivation or other priorities or concerns about engaging in physical activity in public (21). Barriers to exercise motivation include the odds of success, importance of goal, costs, and inclination to remain sedentary (22).

Perceived motivators were defined as the forces acting on or in a person to initiate behaviour (22).

Inclusion/exclusion criteria

Articles were eligible for inclusion if:

- published in a peer-reviewed journal and written in the English language
- participants are human, with a diagnosis of stroke
- they reported data from stroke participants separately from data obtained from participants with other neurological conditions
- perceived barriers and/or motivators were assessed, even if only by asking a single question requiring a YES/NO response, on at least one occasion after stroke, and
- they included individuals over 18 years of age.

Articles were ineligible for the review if they:

- were published in only abstract form
- were published prior to 1966, and
- included participants who had had a transient ischaemic attack rather than a stroke, unless data from the stroke survivors were reported separately.

Search strategy

Electronic searches of four databases (EMBASE, Medline, CINAHL, Psycinfo) identified articles published in English between 1 January 1966 and 30 August 2010. Searches were performed using both Medical Subject Heading (MeSH) terms and key words including 'barriers', 'motivators', 'facilitators', and 'inhibitors'. The search terms were derived from the Cochrane review of physical fitness training after stroke (11). We scrutinized the reference lists of all included articles.

Selection of articles for inclusion

All titles and abstracts were scrutinized by one reviewer (S. C.). If there was insufficient information to determine ineligibility of an article, or if the information from the abstract suggested that it might be eligible, the full article was obtained. S. C. read all full articles and decided whether they fulfilled the inclusion criteria. Three researchers (C. A. G., F. F. S., and F. V. W.) each reviewed a third of all the full articles. This was done independently of the first reviewer. Consensus was reached between S. C. and each researcher regarding which articles were eligible for inclusion in the review.

Data extraction

For each eligible article, S. C. extracted information on study design, aim(s) and objective(s) of the study, characteristics of study participants, methodology used to determine barriers and motivators to physical activity, how barriers and motivators were defined, and identifiable barriers and motivators.

Results

Database (Medline, CINAHL, EMBASE, and Psycinfo) searches identified 86 309 titles and abstracts. After removal of duplicates, articles published prior to 1966 and any articles not published in journal format, 73 807 titles remained. Of these, 57 articles were retrieved as full-text articles, of which six articles fulfilled the inclusion criteria (Fig. 1).

Study characteristics

Six articles describing six separate studies met the inclusion criteria (23–28). Table 1 shows the characteristics of the six articles included in the review (23–28). Five articles (24–28) were qualitative articles, three of which used interviews (25,26,28), one used focus groups (24), and one used both interviews and focus groups (27). All articles were published between 2006 and 2009. Four were performed in the United States (23–25,27), one in Australia (26), and one in the United Kingdom (28).

Participant characteristics and recruitment

The six articles provided data on 174 stroke survivors, ranging from 10 to 83 participants per article. Fifty-seven per cent (99/174) were women. The average age of participants ranged from 54.2 years (23) to 70.5 years (28). Only three articles reported time since stroke onset. Four studies recruited participants from previous research investigating physical activity after stroke (23,24,26,28) and one advertised for volunteers through radio and television advertisements to participate in a trial of exercise after stroke (27). The remaining study recruited 20 stroke survivors who visited different areas within their community and reported the difficulties accessing and participating in physical activity (25).

Perceived barriers and motivators

Four articles reported perceived barriers to physical activity after stroke (23–25,28). Two articles categorized perceived barriers into personal barriers and environmental barriers (23,25). One article also included social policy barriers to participating in physical activity (25). Personal barriers included a lack of motivation, physical difficulties resulting from the stroke, and a lack of knowledge about what to do and how to access services. Environmental barriers included physi-

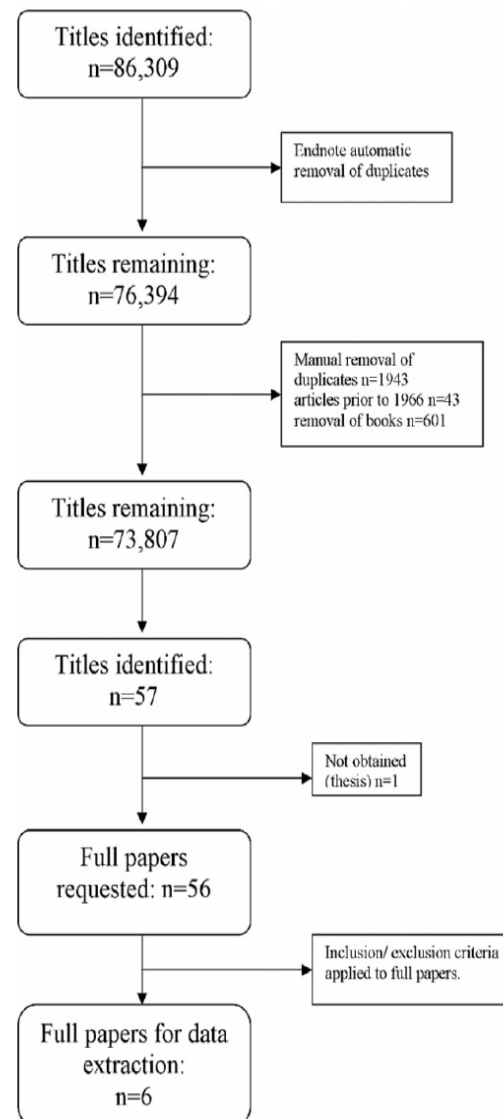


Fig. 1 Review screening process.

cal and transportation access to services and economic costs of taking part in physical activity.

Barriers

The most commonly reported barriers were environmental (access, transport, cost), health problems and stroke-related impairments discouraging activity, embarrassment, and fear of recurrent strokes (23,24,26,28). Physical impairments due to stroke were a barrier to engaging in physical activity (24,27,28). One article reported that a lack of knowledge about how and where to exercise was perceived to be an important barrier to physical activity (23). This study found

Table 1 Demographics of included articles

Article	Year	Country	Study design	Population	Methods	Barriers	Motivators
Damush	2007	United States	Qualitative	<ul style="list-style-type: none"> $n = 13$, 8 males 85% African American, 15% white Mean age 59 years SD 12.3 <12 months post-stroke $n = 20$, 9 males 60% white, 30% African American, 15% Hispanic, 15% other Mean age 55.5 years 	<p>40 stroke survivors from an existing physical activity study. 3. two-hour focus groups, all audio recorded and transcribed.</p> <p>Participants went to identified venues and evaluated: Entryway access, mobility through the site, active engagement with the site, and access throughout the site. They identified barriers and effective strategies to support participation.</p>	<ul style="list-style-type: none"> Perceived stroke impairments discourage activity engagement Lack of motivation Environmental factors <p>Individual barriers:</p> <ul style="list-style-type: none"> physical social cognitive psychological <p>Environmental barriers:</p> <ul style="list-style-type: none"> access (physical, communication, transportation and information technology) public interaction/communications system or policy barriers: national policy accessibility of building/facilities economic resources available to support resources lack of programs offering discounted or free participation benefits. <p>Not reported</p>	<ul style="list-style-type: none"> Finding motivation to exercise Receiving social support to exercise Treating exercise as a specific task or work to do. <p>Not reported</p>
Patterson	2009	Australia	Qualitative	<p>Centre 1:</p> <ul style="list-style-type: none"> $n = 8$, 4 males Mean age 56.6 years SD 14.3 Location of stroke R : L = 5:3 <p>Centre 2:</p> <ul style="list-style-type: none"> $n = 2$ (males) Mean age 63 years SD 2.8 Location of stroke R : L = 2:0 	<p>Patients recruited from exercise maintenance groups. Face-to-face interviews were conducted. Interviews lasted 20–30 mins and were audio-taped</p>	<p>Not reported</p>	<ul style="list-style-type: none"> Exercise opportunity Social opportunity Information hub Motivational support Confidence builder Physical tasks and daily functioning
Resnick	2008	United States	Multi-method qualitative study	<ul style="list-style-type: none"> $n = 29$ 45% female 47% black, 48% white remaining mixed, Hispanic or Asian-Pacific. Mean age 64 years SD 12 Minimum six-months post-stroke 	<p>Participants who completed six-months of treadmill training invited to attend a focus group, or a one-to-one interview. Analysis: basic content analysis and inductive category development.</p>	<p>Not reported</p>	<ul style="list-style-type: none"> Personal goal Psychological benefit Physical benefit Research-based supervised exercise Objective encouragement Verbal encouragement Social support Instrumental activities of daily living Self-determination

Table 1 Continued

Article	Year	Country	Study design	Population	Methods	Barriers	Motivators
Rimmer	2008	United States	Retrospective analysis	<ul style="list-style-type: none"> $n = 83$ 70% female Mean age 54.2 years SD 8.2 African American 80%, Hispanic 10%, white 9%, other 1% 	Participants recruited to participate in a health-promotion program. The Barriers to Physical Activity and Disability Survey was administered to participants over the phone by trained staff. Participants were given statements and asked if they felt each were a barrier or not to physical activity.	Environmental/Facility: (percentage of participants that reported specific barrier) <ul style="list-style-type: none"> Cost of program 61% Lack of transportation 57% Not aware of fitness centre in the area 57% Don't feel trainer in facility is able to help 36% Not comfortable in exercising in a facility 26% Personal: <ul style="list-style-type: none"> Don't know how to exercise 46% Don't know where to exercise 44% Lack of energy 39% Lack of motivation 37% Exercise won't improve my condition 36% I'm too lazy to exercise 33% Health concerns prevent me from exercising 28% Exercise is too difficult 20% Exercise is boring or monotonous 18% Lack of interest 16% Lack of time 11% Exercise will make my condition worse 1% 	Not reported
Robison	2009	United Kingdom	Qualitative	<ul style="list-style-type: none"> $n = 19$, 11 males Mean age 70.5 years SD 8.6 12 months post-stroke 	Blocked purposeful selection strategy used to identify and recruit participants. Audio recorded interviews at discharge and 12 months post-stroke.	<ul style="list-style-type: none"> Physical or cognitive disability Environmental influences 	<ul style="list-style-type: none"> Adaptability of the individual Support from significant others Professional support

N, number of patients; SD, standard deviation; RCT, randomized controlled trial; R L, right compared to left.

that 28% of participants stated that health concerns prevented them from taking part in physical activity and 36% of study participants reported that they did not feel that physical activity would help their condition (23). Four articles reported perceived barriers; of these, only two of them reported lack of motivation as a barrier (23,24).

Motivators

The most commonly reported perceived motivator to physical activity was the possibility of meeting other people with stroke which provided psychological and social support for participants (24,26–28). Two articles reported that group exercise classes provided motivation to increasing physical activity as participants did not want to let class members down by non-attendance (24,27). The desire to carry out normal daily tasks was a motivator that was reported in three of four studies which investigated motivators (24,26,27). One study reported that the desire to carry out normal tasks was a strong motivator to be physically active. Specifically, the male participants of this study reported that exercise allowed a more rapid return to driving (27). The other commonly reported motivator was the benefit of professional support in guiding and facilitating physical activity (26–28). However, one study reported that although patients did receive professional support (mainly from physiotherapists) in the community; patients were typically disappointed with professional services (28). This was because professional services ended too quickly and were not effective in helping patients to resume certain aspects of their former way of life (28).

Discussion

This review encompassed all perceived barriers and motivators, i.e. physical and environmental as well as psychosocial, and focussed on studies which included only stroke survivors. The review included both qualitative and quantitative data. We were selective about which articles truly reflected the perceived barriers and motivators of stroke survivors; hence, our review has found some differing studies to the previous review. The previous review concluded that self-efficacy, physical activity beliefs, and social support were particularly relevant to physical activity behaviour after stroke and should be included in theoretically based physical interventions (19). Our current review has added to this because we have demonstrated that environmental factors, health concerns, and a lack of motivation were also perceived barriers. Our review found that the desire to perform daily tasks was a common perceived motivator to physical activity.

Our systematic review showed that perceived barriers and motivators to physical activity reported by stroke survivors are similar to the findings from other patient groups. A lack of motivation is a commonly reported barrier to exercise in patients with spinal cord injury (29), participants attending cardiac rehabilitation (30), and also healthy community-dwelling women (31). Similarly, environmental factors have

been reported as a barrier to participation by persons with disability (32). Professional support has been identified in studies including other patient groups such as older primary care patients (33). Social support has previously been reported by many groups including women who are overweight (34).

Strengths of this review

Our searches identified both qualitative and quantitative articles. This enabled us to use detailed data from stroke survivors' experiences as well as understand the frequency of specific barriers and motivators being reported. Including both qualitative articles and quantitative articles in this review enabled us to collate all important aspects of barriers and motivators to physical activity post-stroke.

Limitations of this review

As there were no specific MeSH headings for barriers and motivators, we relied heavily on key words. Our key words included searching 'barriers' and 'motivators' as well as 'facilitators' and 'inhibitors' enabling us to retrieve a broad range of articles. Thus, our electronic search identified a large number of titles and abstracts that were clearly not relevant to the review. While more theoretical terms such as 'outcome expectation' and 'behavioural belief' could have been utilized, this may have reduced the number of citations resulting in missing relevant articles.

A limitation of our review is that we searched for only English language articles, which may have excluded potentially relevant articles.

Strengths and limitations of the included articles

Qualitative methodology was a strength of five of the articles (24–28). Qualitative methodology allows in-depth data to be elicited with the full scope of participants' experiences and perspectives being captured and not limited to the answers of a questionnaire (35). A limitation of the included articles was that none provided a definition of physical activity. 'Physical activity', 'exercise', and 'physical fitness' are terms that describe different concepts; however, they are often used interchangeably (20). In this review, three articles focussed on perceived barriers and motivators to 'exercise' (24,26,27). The remaining three focussed on 'physical activity' (23,25,28); however, one article called this 'community participations' (25) and one called this 'valued activity' (28), terms which might have a different meaning as specified in the International Classification of Functioning, Disability and Health (36). 'Valued activities' were classified as activities relating to employment, domestic life, and social roles including driving, hobbies, sports, or social activities (28). This was thought to include 'physical activity' as they incorporated activities that were produced by the contraction of skeletal muscle that increases energy expenditure (20). 'Community participation' involves being part of and actively engaging in a community and

having equal access and the right to participate in the community (25). Participants reported wanting to be mobile in the community and to be able to access services in the community (25). 'Community participation' was therefore deemed to be part of physical activity (20). The lack of clear definitions in the included articles of what constituted physical activity after stroke, presents challenges to researchers, as researchers' definitions may be different from participants'. Individual participant's definition of physical activity may also differ.

Our review has highlighted only six relevant articles. It is essential to determine the generalizability of these articles to the wider stroke population. Four of the six articles recruited participants who were already participating in articles of physical activity after stroke (23,24,26,28). It is likely that the views of these participants may differ from those stroke survivors who declined to participate in physical activity research. The average age of participants in the articles ranged from 54.2 years (23) to 70.5 years (28) yet the average reported age for stroke onset is 75 years (37). This reduces the generalizability of the results, as included participants were younger with possibly fewer age-related conditions resulting in different perceptions of barriers to physical activity. Stroke survivors in different countries may differ in their views on physical activity. Therefore, as the geographical distribution of the included articles is limited to the United States, United Kingdom, and Australia, the generalizability of our review may be limited.

Implications for future research

This systematic review has shown that data are beginning to emerge in the area of perceived barriers and motivators to physical activity after stroke. This review highlights that further research is needed, particularly in countries outside the United States, which recruit people with a range of disabilities who have not previously participated in an exercise trial. This would enable stroke teams to gain a better understanding of how to motivate stroke survivors to increase physical activity. In the meantime, this review does portray specific information for healthcare professionals who work with stroke survivors providing advice and support to patients and their carers.

The perceived barriers identified in this systematic review included those likely to reduce self-efficacy, i.e. individuals' beliefs that they can engage in the activity. In Social Cognitive Theory (38), control beliefs are conceptualized as self-efficacy, defined in terms of beliefs about capabilities to execute behaviours. According to this theory, an individual may believe they must take responsibility for their health but fail to do so as they do not believe they can do what is necessary. A prospective cohort study within a RCT of stroke survivors has shown the importance of perceived behavioural control to increasing physical activity post-stroke (39,40). The cohort study showed walking limitations and walking recovery after stroke was predicted by stroke survivors' perceived behaviour control (39). The RCT that this predictive cohort was imbedded into tested

an intervention designed to increase stroke survivors' control beliefs by addressing barriers to physical activity (40). The intervention led to significantly better recovery from disability, allowing for initial disability, than those in the control group (40).

Implications for practice

We now need to translate the perceived barriers and motivators to physical activity after stroke into long-term behavioural change interventions. This review highlights that the resumption or initiation of physical activity post-stroke does not solely depend on the individual. Uptake of physical activity may be dependent on the help and support received from healthcare professionals (25–27) as well as social networks. Healthcare professionals need to be aware of the barriers perceived by stroke survivors. Understanding perceived barriers will enable healthcare professionals to deliver more focused support and guidance to stroke survivors. Concern about the adverse effects of exercising is a perceived barrier to physical activity for stroke survivors (23,28). This suggests that participants may be unaware of the benefits of physical activity. This barrier may be overcome by having healthcare professional educating stroke survivors on the actual low risks of being physical activity after stroke while highlighting the benefits of physical activity. One study highlights that rehabilitation services tend to focus on the patients, or patients and primary carer, yet patients are members of extended families, communities, and wider communities (28). As social factors were a strong motivation for physical activity, engagement with all these individuals is essential to allow the resumption of a normal life post-stroke (28).

Only two of the articles that reported barriers found lack of motivation as a perceived barrier (23,24). This suggests that many stroke survivors may wish to be more physically active, yet other barriers other than lack of motivation are important.

Conclusion

Understanding the perceived barriers and motivators to physical activity after stroke is a new and developing area. The articles included in this review support the emerging consensus about the need for long-term support for exercise after stroke services. This review will pave the way for the development of physical activity interventions after stroke that address relevant perceived barriers and motivators to physical activity perceived by stroke survivors. By understanding perceived barriers and motivators, we will be able to tailor interventions to target barriers, while building upon perceived motivators, to increase and maintain stroke survivors' physical activity.

Acknowledgements

The study was funded by The Stroke Association, through a Junior Research Fellowship award to Sarah Nicholson.

References

- Gordon NF, Gulanick M, Costa F *et al.* Physical activity and exercise recommendations for stroke survivors: an American Heart Association scientific statement from the Council on Clinical Cardiology, Subcommittee on Exercise, Cardiac Rehabilitation, and Prevention; the Council on Cardiovascular Nursing; the Council on Nutrition, Physical Activity, and Metabolism; and the Stroke Council. *Stroke* 2004; 35:1230–40.
- Bernhardt J, Dewey H, Thrift A, Donnan G. Inactive and alone: physical activity within the first 14 days of acute stroke unit care. *Stroke* 2004; 35:1005–9.
- Rand D, Eng JJ, Tang PF, Jeng JS, Hung C. How active are people with stroke?: use of accelerometers to assess physical activity. *Stroke* 2009; 40:163–8.
- Saunders DH, Greig CA, Young A, Mead GE. Association of activity limitations and lower-limb explosive extensor power in ambulatory people with stroke. *Arch Phys Med Rehabil* 2008; 89:677–83.
- Deplanque D, Masse I, Lefebvre C, Libersa C, Leys D, Bordet R. Prior TIA, lipid-lowering drug use, and physical activity decrease ischemic stroke severity. *Neurology* 2006; 67:1403–10.
- Deplanque D, Masse I, Libersa C, Leys D, Bordet R. Previous leisure-time physical activity dose dependently decreases ischemic stroke severity. *Stroke Res Treat* 2012; 2012: article ID 614925 doi:10.1155/2012/614925.
- Krurup LH, Truelsen T, Glud C *et al.* Prestroke physical activity is associated with severity and long-term outcome from first-ever stroke. *Neurology* 2008; 71:1313–18.
- Stroud N, Mazwi TM, Case LD *et al.* Prestroke physical activity and early functional status after stroke. *J Neurol Neurosurg Psychiatry* 2009; 80:1019–22.
- Lee CD, Folsom AR, Blair SN. Physical activity and stroke risk: a meta-analysis. *Stroke* 2003; 34:2475–81.
- Hackam DG, Spence JD. Combining multiple approaches for the secondary prevention of vascular events after stroke: a quantitative modelling study. *Stroke* 2007; 38:1881–5.
- Brazzelli M, Saunders DH, Greig CA, Mead GE. Physical fitness training for stroke patients. *Cochrane Database Syst Rev* 2011; (11):CD003316.
- Mead GE, Greig CA, Cunningham I *et al.* Stroke: a randomized trial of exercise or relaxation. *J Am Geriatr Soc* 2007; 55:892–9.
- Mead G, Bernhardt J. Physical fitness training after stroke, time to implement what we know: more research is needed. *Int J Stroke* 2011; 6:506–8.
- Brainin M, Norrving B, Sunnerhagen KS *et al.* Poststroke chronic disease management: towards improved identification and interventions for poststroke spasticity-related complications. *Int J Stroke* 2011; 6:42–6.
- Becker MH, Maiman LA. Sociobehavioral determinants of compliance with health and medical care recommendations. *Med Care* 1975; 13:10–24.
- The Scottish Government. Sport, exercise and physical activity: public participation, barriers and attitudes; 2006. Available at <http://www.scotland.gov.uk/Publications/2006/09/29134901/0> [cited 6 September 2011].
- Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promot Int* 2000; 15:259–67.
- Boysen G, Krurup LH, Zeng X *et al.* ExStroke Pilot Trial of the effect of repeated instructions to improve physical activity after ischemic stroke: a multinational randomised controlled clinical trial. *BMJ* 2009; 339:b2810.
- Morris J, Oliver T, Kroll T, MacGillivray S. The importance of psychological and social factors in influencing the uptake and maintenance of physical activity after stroke: a structured review of the empirical literature. *Stroke Res Treat* 2012; 2012: article ID 195249; doi:10.1155/2012/195249.
- Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise and physical fitness: definitions and distinctions for health-related research. *Public Health Rep* 1985; 100:126–31.
- Allison KR, Dwyer JJ, Makin S. Perceived barriers to physical activity among high school students. *Prev Med* 1999; 28:608–15.
- Ryan RM, Deci EL. Intrinsic and extrinsic motivations: classic definitions and new directions. *Contemp Educ Psychol* 2000; 25:54–67.
- Rimmer JH, Wang E, Smith D. Barriers associated with exercise and community access for individuals with stroke. *J Rehabil Res Dev* 2008; 45:2315–22.
- Damush TM, Plue L, Bakas T, Schmid A, Williams LS. Barriers and facilitators to exercise among stroke survivors. *Rehabil Nurs* 2007; 32:253–60.
- Hammel J, Jones R, Gossett A, Morgan E. Examining barriers and supports to community living and participation after a stroke from a participatory action research approach. *Top Stroke Rehabil* 2006; 13:43–58.
- Patterson S, Ross-Edwards B. Long-term stroke survivors' needs and perceptions of an exercise maintenance model of care. *Int J Ther Rehabil* 2009; 16:659–69.
- Resnick B, Michael K, Shaughnessy M, Kopunek S, Nahm ES, Macko RF. Grand rounds. Motivators for treadmill exercise after stroke. *Top Stroke Rehabil* 2008; 15:494–502.
- Robison J, Wiles R, Ellis-Hill C, McPherson K, Hyndman D, Ashburn A. Resuming previously valued activities post-stroke: who or what helps? *Disabil Rehabil* 2009; 31:1555–66.
- Scelza WM, Kalpakjian CZ, Zemper ED, Tate DG. Perceived barriers to exercise in people with spinal cord injury. *Am J Phys Med Rehabil* 2005; 84:576–83.
- Evenson KR, Fleury J. Barriers to outpatient cardiac rehabilitation participation and adherence. *J Cardiopulm Rehabil* 2000; 20:241–6.
- Nies MA, Vollman M, Cook T. Facilitators, barriers, and strategies for exercise in European American women in the community. *Public Health Nurs* 1998; 15:263–72.
- Rimmer JH, Riley B, Wang E, Rauworth A, Jurkowski J. Physical activity participation among persons with disabilities: barriers and facilitators. *Am J Prev Med* 2004; 26:419–25.
- Damush TM, Stump TE, Saporito A, Clark DO. Predictors of older primary care patients' participation in a submaximal exercise test and a supervised, low-impact exercise class. *Prev Med* 2001; 33:485–94.
- Young DR, Gittelsohn J, Charleston J, Felix-Aaron K, Appel LJ. Motivations for exercise and weight loss among African-American women: focus group results and their contribution towards program development. *Ethn Health* 2001; 6:227–45.
- Barbour RS. The role of qualitative research in broadening the 'evidence-base' for clinical practice. *J Eval Clin Pract* 2000; 6:155–63.
- World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva, World Health Organization, 2001.
- Rudd T. Stroke [updated 2009]. Available at http://www.bgs.org.uk/index.php?option=com_content&view=article&id=378:stroke&catid=12:goodpractice&Itemid=106 [cited 8 September 2011].
- Bandura A. Self-Efficacy – the Exercise of Control. New York, W.H. Freeman & Company, 1997.
- Bonetti D, Johnston M. Perceived control predicting the recovery of individual-specific walking behaviours following stroke: testing psychological models and constructs. *Br J Health Psychol* 2008; 13:463–78.
- Johnston M, Bonetti D, Joice S *et al.* Recovery from disability after stroke as a target for a behavioural intervention: results of a randomized controlled trial. *Disabil Rehabil* 2007; 29:1117–27.

3.4. Discussion

This systematic review sought to determine all factors that influence the uptake of physical activity after stroke and included both qualitative and quantitative data. Social motivation and the desire to perform daily tasks were the most commonly reported perceived facilitators to physical activity after stroke. The most commonly reported perceived barriers were: environmental factors (access, transport, and cost) and health concerns/stroke impairments discouraging physical activity due to perceived inability, embarrassment and fear of recurrent strokes. These results show that stroke survivors appear to be willing to be physically active, especially if they hold the belief that physical activity will allow them to maintain their independence. However, fear and embarrassment may prevent physical activity uptake in those who have the desire to be physically active. This was due to them being conscious that they have had a stroke, the potential worry of having another one and the worry about the perceptions of other people when they are taking part in physical activity. These concerns may influence the self-efficacy of the stroke survivors, as they may believe that they are unable to increase their physical activity due to negative affect arising from these fears.

At the same time as our review was published a systematic review examining the psychological and social factors that influence the uptake and maintenance of physical activity after stroke was also published (Morris et al., 2012). The review found that self-efficacy, physical activity beliefs and social support appeared to be particularly important to altering physical activity behaviour in stroke survivors (Morris et al., 2012). However, Morris' review focussed on only psychological and

social factors and did not include physical or environmental factors that influence physical activity uptake. For example, environmental barriers such as lack of transport may be important to stroke survivors who are unable to drive due to their stroke. Furthermore the review included five studies where stroke survivors' data were interspersed with participants with other conditions (e.g. multiple sclerosis, joint and connective tissue disease and spinal cord injury), which may have influenced interpretation of the results (Morris et al., 2012).

The systematic review conducted as part of this programme of work differed from that published by Morris et al (2012). The review for this PhD thesis did not include articles that mixed stroke survivors view on barriers and facilitators with other patients who had differing neurological conditions. It was decided not to include these articles to ensure included articles accurately reflected the perceived barriers and facilitators of only those affected by stroke. For this reason this systematic review identified different studies compared with Morris et al (2012). However, there were four studies that overlapped between the two reviews including: (Damush et al., 2007, Rimmer et al., 2008, Resnick et al., 2008, Patterson and Ross-Edwards, 2009).

3.4.1. Review update

The results of the systematic review were based on a database search until 30th of August 2010. Due to time constraints, it was not possible to conduct an update of this systematic review yet it was likely that new evidence had emerged in the following five years. Therefore a brief update on the review was performed in the Edinburgh University DiscoverED database using key words such as “stroke” “barriers” “facilitators” and “physical activity” to determine if there had been any significant

articles published between August 2010 and October 2016. The search (conducted on 7/10/2016) indicated that five new articles (describing four studies) had been published since the systematic review (Morris et al., 2015, Morris et al., 2016, Jellema et al., 2016, Signal et al., 2016, Outermans et al., 2016). However, these studies do not greatly influence conclusions drawn in chapters 3-5 in this thesis. One recent qualitative study interviewing 38 community dwelling stroke survivors reported that social and environmental influences were important in the uptake of physical activity after stroke (Morris et al., 2015, Morris et al., 2016). Social and environmental influences were also found as part of the qualitative study conducted in chapter four of this PhD and therefore were incorporated in the behaviour change intervention (Nicholson. et al., 2014). Similarly a recent systematic review of 69 qualitative, quantitative and mixed-design studies investigated the environmental barriers influencing the resumption of valued activities post stroke (Jellema et al., 2016). This review again highlighted the importance of both social and environmental factors to the uptake of physical activity after stroke (Jellema et al., 2016). Therefore, neither of these studies would have influenced the development of the behaviour change intervention or the conclusions of this PhD. Another study conducted since the review was a qualitative study comprising of focus groups and interviews (including 36 stroke survivors) to investigate the barriers to outdoor walking in stroke survivors (Outermans et al., 2016). This study found that personal factors determined the intention to walk outdoors, e.g., negative social influence resulting from restrictive caregivers in the social environment, low self-efficacy influenced by physical environment, and also negative attitude towards physical activity (Outermans et al., 2016). Opportunities arising from household

responsibilities and lively social constructs facilitated outdoor walking (Outermans et al., 2016). The qualitative study (chapter four) found social interaction, beliefs of the benefits of exercise, high self-efficacy and the necessity to perform routine behaviours all played an important role in the uptake of physical activity after stroke. Therefore, this study would not have influenced the development of the behaviour change intervention or the conclusions of this PhD. The final study identified by the updated search examined the barriers and facilitators stroke survivors perceived when engaging in high-intensity exercise (Signal et al., 2016). As high-intensity exercise was not the focus of this PhD, the results of this study would not have great impact on the conclusions of this body of work.

3.5. Conclusions

Understanding the perceived barriers and facilitators to physical activity after stroke is an understudied yet developing area. This systematic review begins to give some understanding of the perceived barriers and facilitators to physical activity after stroke. However, there were a limited number of studies that fulfilled the inclusion criteria for the review, with only one qualitative study being undertaken in the UK. Further UK based qualitative studies are therefore required to provide up to date, rich and descriptive data.

The systematic review has also highlighted the importance of control beliefs (such as self-efficacy) in the uptake of physical activity after stroke. As part of an earlier small-scale study, quantitative data on barriers, facilitators, self-efficacy and intention to physical activity after stroke were collected but not analysed (Carroll et

al., 2012). In light of the findings of the systematic review, suggesting the importance of self-efficacy and highlighting the lack of UK studies on barriers and facilitators to physical activity after stroke, it was appropriate to retrospectively analyse these data, obtained from 50 participants on discharge from hospital after an acute stroke. This analysis would provide valuable information on not only self-efficacy of stroke survivors at hospital discharge but also on perceived barriers and facilitators to physical activity at discharge from hospital. Furthermore, these data would be unlike the previous studies included in the systematic review where barriers and facilitators were analysed six months or more post hospital discharge. The take home messages from this systematic review are detailed in table two.

Table 2: Systematic review summary

Systematic review summary
<ul style="list-style-type: none">• Systematic reviews are regarded as the strongest form of evidence as they apply strategies to reduce bias• There were very few studies that fulfilled the inclusion criteria and were included as part of the review• Only one of these studies was conducted in the UK• Commonly reported perceived barriers were environmental factors (e.g. transport and access), health concerns and stroke impairments.• Commonly reported perceived facilitators were social support and the need to be able to perform daily tasks.• The perceived barriers and facilitators identified in this review indicate the importance of self-efficacy and intentions towards physical activity• These are areas that need to be examined further, especially near discharge from hospital when an intervention is likely to take place.

CHAPTER 4 Qualitative analysis of the perceived barriers and facilitators to physical activity after stroke

4.1. Introduction

This chapter further investigates the perceived barriers and facilitators to physical activity after stroke using qualitative analysis. A qualitative interview study would provide descriptive data from real-time stroke survivors, recruited from within the geographical area that the proposed behaviour change intervention would be undertaken. The results of this qualitative interview study have been published in the journal “Disability and Rehabilitation” (Nicholson. et al., 2014). All the recruitment, interviews, analysis of the interviews and drafting of the manuscript was carried out by SN. MD also helped with the analysis of the interviews and all of the authors provided comments and edited the final draft prior to publication. NHS ethical approval was obtained for this study from the South East Scotland Research Ethics Committee 01 on the 28th of September 2010. A copy of the ethical approval can be found in appendix two. A copy of the participant information sheet and consent form for this study can be found in appendix three.

4.2. Background

In order to support stroke survivors to become physically active, it is important to understand what stroke survivors perceive as the barriers and facilitators to physical activity. Perceived barriers and facilitators influence the likelihood of an individual performing in a specific behaviour, such as physical activity (Becker et al., 1977). The systematic review (chapter three) highlighted the limited number of studies examining the barriers and facilitators perceived by stroke survivors towards

physical activity, especially within the UK (Nicholson et al., 2013). Therefore, it was judged necessary to carry out a qualitative interview study to investigate perceived barriers and facilitators to physical activity after stroke to a local Edinburgh population.

Content framework analysis was performed by coding the interview transcripts to the original TDF (Michie et al., 2005). The background to the TDF and the reasons for its inclusion in this thesis have been discussed in section 1.16.2. The aim of the TDF is to simplify and combine a plethora of behaviour change theories. The TDF was chosen for the analysis of the semi-structured interviews due to its inclusiveness of all motivational, action and organisational theories of behaviour.

Content analysis is a widely used technique in qualitative research, where the meaning of the text in a transcript is systematically described (Mayring, 2014). This is done by assigning successive parts of a transcript to the categories of a coding framework- in this case the TDF. Although often reductive in its nature, qualitative content analysis is very systematic and helps to reduce large quantities of data (Mayring, 2014). This approach was deemed appropriate to use for the analysis of the interviews as the overall aims was to use the data obtained from the interviews to develop a behaviour change intervention. This would be done using the TDF and associated BCTs to determine what was most appropriate for the behaviour change intervention. Therefore, the qualitative interviews needed to be coded in accordance with the domains of the TDF.

4.3. Published paper

RESEARCH PAPER

A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity

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Abstract

Purpose: After stroke, physical activity and physical fitness levels are low, impacting on health, activity and participation. It is unclear how best to support stroke survivors to increase physical activity. Little is known about the barriers and facilitators to physical activity after stroke. Thus, our aim was to explore stroke survivors' perceived barriers and facilitators to physical activity. **Methods:** Semi-structured interviews with 13 ambulatory stroke survivors exploring perceived barriers and facilitators to physical activity post stroke were conducted in participants' homes, audio-recorded and transcribed verbatim. The Theoretical Domains Framework (TDF) informed content analysis of the interview transcripts. **Results:** Data saturation was reached after interviews with 13 participants (median age of 76 years (inter-quartile range (IQR) = 69–83 years). The median time since stroke was 345 d (IQR = 316–366 d). The most commonly reported TDF domains were "beliefs about capabilities", "environmental context and resources" and "social influence". The most commonly reported perceived motivators were: social interaction, beliefs of benefits of exercise, high self-efficacy and the necessity of routine behaviours. The most commonly reported perceived barriers were: lack of professional support on discharge from hospital and follow-up, transport issues to structured classes/interventions, lack of control and negative affect. **Conclusions:** Stroke survivors perceive several different barriers and facilitators to physical activity. Stroke services need to address barriers to physical activity and to build on facilitators to promote physical activity after stroke.

► Implications for Rehabilitation

- Physical activity post stroke can improve physical fitness and function, yet physical activity remains low among stroke survivors.
- Understanding stroke survivors' perceived barriers and facilitators to physical activity is essential to develop targeted interventions to increase physical activity.
- Beliefs about capabilities, environmental context and resources and social influences were the mostly commonly report influences on stroke survivors' perceived barriers and facilitators to physical activity.

Introduction

Globally, stroke affects about 16 million people each year [1] and is the leading cause of adult disability [2]. Recovery from a stroke is a continuous process over many months or even years. Therefore, attention needs to be placed on how to facilitate

long-term recovery from stroke and to support the needs of stroke survivors with residual post-stroke problems [3].

After stroke, physical activity [4] and fitness levels [5] are low and impaired physical fitness is associated with activity limitations [6]. There is an increasing body of evidence that physical fitness training improves physical fitness, aspects of walking (e.g. speed, tolerance and independence during walking) and reduces activity limitations [7]. Furthermore, it is well established that a low level of physical activity is a risk factor for a first stroke. It is biologically plausible that low physical activity is also a risk factor for recurrent stroke and other vascular events. Risk-modelling studies have suggested that the risk of recurrent

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Keywords

Barriers, facilitators, physical activity, stroke

History

Received 11 July 2012

Revised 4 December 2013

Accepted 9 December 2013

Published online 31 December 2013

stroke could be reduced by about 20% with physical activity [8]. Physical activity is recommended for stroke survivors in several national clinical guidelines, including guidelines from the American Heart Association and Scottish Intercollegiate Guidelines [9,10].

In order to support stroke survivors to become physically active, it is important to understand what stroke survivors perceive as the barriers and facilitators to physical activity. Perceived barriers and facilitators influence the likelihood of an individual performing in a specific behaviour, such as, physical activity [11]. It is unclear whether stroke survivors' perceived barriers and facilitators differ from those of the general population. Differences may be evident for a number of reasons, including residual neurological deficits, emotional difficulties and restricted physical access to community resources. To date, few publications have examined perceived barriers and motivators to physical activity post stroke. A recent review examined the psychological and social factors that influence the uptake and maintenance of physical activity after stroke [12]. The review found that self-efficacy, physical activity beliefs, and social support appeared to be particularly relevant to physical activity behaviour [12]. However, the review focussed only on psychological and social factors and not on physical or environmental factors that might influence physical activity uptake. According to the International Classification of Functioning, Disability and Health (WHO, 2001), personal factors (e.g. age, gender and coping styles) as well as environmental factors (e.g. cultural and family beliefs) together make up contextual factors and therefore should both be considered in an individual's experience of their health condition [13]. In order to consider both personal and environmental influences on behaviour, we have chosen to use the Theoretical Domains Framework (TDF) to identify barriers and facilitators to physical activity perceived by stroke survivors' [14].

This framework was chosen due to its inclusive nature, incorporating both personal and environmental contextual influences on behaviour. The TDF comprises 12 domains of theory-based explanations for behaviour, which resulted from a comprehensive review of behavioural theories. Constructs of all motivational, action and organisational theories of behaviour were reviewed and constructs were divided into domains based on their commonalities [14]. The TDF covers a comprehensive range of scientific explanations for behaviour and behaviour change [14]. The domains include: "knowledge", "skills", "social role and identity", "beliefs about capabilities", "beliefs about consequences", "motivation and goals", "nature of the behaviour", "environmental context and resources", "social influences", "social identity", "emotion" and "behavioural regulation".

Methods

Participants

Fifty participants from a previous study which determined the feasibility and accuracy of pedometers in measuring step count after stroke [15] were randomly listed (i.e. numbers 1–50 were randomly generated by computer and these corresponded to participants' numbers from the previous study). Medical records were checked to determine whether participants were still alive, and then participants were contacted in this random order. Thirteen participants participated in this qualitative study (Table 1). Participants were able to walk independently, with or without walking aids, had capacity to give informed consent and medically stable. All were retired. Participants provided written, informed consent prior to participation.

Participants with communication difficulties were not excluded if they had capacity to give informed consent.

Table 1. Participant demographics.

Demographic variable	Number of participants
Gender:	
Male	5 (38.5%)
Female	8 (61.5%)
Age (median, IQR):	76 years (69–83)
Stroke type	
Haemorrhagic	1 (8%)
Ischaemic	12 (92%)
OCSF classification	
LACS	4 (30.8%)
PACS	5 (38.4%)
POCS	2 (15.4%)
TACS	0
Unknown	2 (15.4%)
Time since stroke (median, IQR)	
Working prior to stroke:	345 d (316–366)
Retired/not working	13 (100%)
Working	0 (0%)

IQR, inter quartile range; OCSF, Oxford Community Stroke Project; LACS, lacunar stroke; PACS, partial anterior circulation stroke; POCS, posterior circulation stroke; TACS, total anterior circulation stroke.

Discussion with speech and language therapists allowed us to determine the best ways to communicate with participants with communication difficulties. Only one participant had communication difficulties, this participant used a note-pad when they had difficulty answering questions. There were no additional exclusion criteria for the current study.

Procedure

Semi-structured one-to-one interviews were conducted to explore perceived barriers and facilitators to physical activity after stroke. Interviews were deemed more appropriate than focus groups to prevent participants influencing the views of fellow participants. Interviews were conducted in the participants' homes. Spouses/carers were invited to listen and participate in the interviews. Interviews were audio recorded and transcribed verbatim. All interviews were conducted by one researcher (S. N.). A detailed topic guide is shown in the Appendix 1 – this included general questions about life after stroke, and questions about attitudes and experiences of physical activity.

Sample size/data saturation

Data saturation was established using four standard principles for analysis and reporting of data saturation in qualitative work [16]. These include (a) *a priori* specifying initial sample size (b) *a priori* specifying the number of additional interviews to be conducted without new shared themes or ideas emerging before data saturation can be assumed (i.e. stopping criterion), (c) analysis should be conducted by at least two independent coders and agreement reported to establish that the analysis is robust and reliable, and (d) reporting of data saturation methods and findings. We planned a first round of 10 interviews with a stopping criterion of three additional interviews to achieve data saturation. Therefore, we contacted participants until 10 agreed to participate before contacting a further three participants. The first 10 interviews were analysed before conducting the next three interviews. A total of 13 interviews were necessary for data saturation. The stopping criterion was tested after each successive interview (i.e. after 11, 12 and 13) to ensure no additional information was obtained in these interviews [16]. No new themes emerged in the final three interviews, therefore data saturation had been achieved (see Table 2).

Table 2. Data saturation tables.

Constructs	Domains		Knowledge		Skills		Nature of behaviour		Beliefs about capabilities				Memory and attention		Beliefs about consequences				Social identity	
	Importance of PA	Lack of knowledge about PA	Coping strategy	Routine behaviour	Acceptance	High self efficacy	Low self efficacy	Perceived competence	Empowerment	Beliefs about aging	Lack of control	Prior health issues	Self confidence	Attention difficulties	Fear of stigma	Fear of falling	Triggering another stroke	Unrealistic optimism	Self identity	Professional identity
Interview																				
1	X		X	X		X			X				X						X	X
2				X			X					X	X	X		X			X	X
3	X			X		X			X			X	X				X	X	X	X
4		X		X		X			X			X	X				X	X	X	X
5		X		X	X	X			X			X	X		X		X	X	X	X
6	X			X	X	X			X			X	X		X					
7	X			X	X	X			X			X	X		X					
8	X	X		X		X	X					X	X							
9	X			X		X		X		X		X	X	X	X	X			X	
10	X			X		X														
11	X			X		X														
12			X	X		X														
13				X		X			X		X	X	X	X					X	

(continued)

(continued)

Table 2. Continued.

Domains	Environmental context and resources				Motivation			Emotion				Social influences				Behavioural regulation							
	Economic constraints	Environmental constraints	Lack of professional services	Professional support	Transport	Exti motivation-previouslly enjoyed activity	Exti motivation-attending exercise classes	Intrinsic motivation	Motivation from feedback	Lack of motivation	Neg. affect - fatigue	Neg. affect - pain	Neg. affect - frustration	Fear of falling	Positive affect	Lack of professional services	Professional support	Family support	Lack of family support	Overprotection	Enjoying social interaction	Action planning	Target Setting
Interview																							
1			X	X	X		X		X			X		X	X	X	X	X	X			X	
2			X	X	X		X		X			X		X	X	X	X	X	X			X	
3			X	X	X		X		X			X		X	X	X	X	X	X			X	
4			X	X	X		X		X			X		X	X	X	X	X	X			X	
5			X	X	X		X		X			X		X	X	X	X	X	X			X	
6	X			X	X		X		X			X		X	X	X	X	X	X			X	
7				X	X		X		X			X		X	X	X	X	X	X			X	
8	X						X		X			X		X	X	X	X	X	X			X	
9							X		X			X		X	X	X	X	X	X			X	
10							X		X			X		X	X	X	X	X	X			X	
11							X		X			X		X	X	X	X	X	X			X	
12							X		X			X		X	X	X	X	X	X			X	
13							X		X			X		X	X	X	X	X	X			X	

Analysis

Content analysis was performed by coding the interview transcripts to the TDF [14]. Table 3 shows the constructs of each domain as described in Michie's paper [14]. Two researchers (S. N. and M. D.) read the transcripts and independently identified the evident domains, by highlighting the quotes in the text and assigning them to one or more of the 12 domains. A single quote could be placed into more than one domain. Perceived barriers and facilitators were identified in each transcript. The quotes about perceived barriers and facilitators were then compared to the constructs that form each domain (see Table 3) to determine which of the domains the quotes fitted into. The quotes within each domain, selected independently, were then cross-checked by both researchers. The frequency each perceived barrier or facilitator was mentioned was also noted. A series of matrices were developed using Excel software to record all the responses in each domain. Responses were identified by participant code, page and line number in order to determine response frequency and to identify similar responses from the same participant. Text was displayed thematically and rows sorted to order respondents in each domain. This process facilitated both within-participant and between-participant analyses [17].

Results

Table 2 shows that no new themes emerged in the final three interviews, therefore data saturation had been achieved (see Table 2). Interviews were conducted with 13 participants (eight women and five men) (Table 1). Their median age was 76 years (IQR = 69–83) and the median time since stroke was 345 d (IQR = 316–366). Results are reported in relation to the 12 domains of TDF, and quotations from participants' transcripts are included to illustrate these findings.

Theoretical domains framework

The transcripts provided data from all of the 12 domains. All perceived barriers and facilitators emerging from the transcripts could be fitted into one of the 12 domains. The most commonly reported domains were beliefs about capabilities, environmental context and resources, and social influences, while the least commonly reported were skills and memory and attention.

Knowledge

"Knowledge" refers to the participant's understanding of the importance of being physically active post stroke. Knowledge was perceived both as a facilitator and barrier to physical activity post stroke. Knowledge that physical activity was beneficial to stroke recovery acted as a facilitator.

"Well, instil into them that activity is the best way forward, isn't it? It's the only way they'll get back to where they were". 11:296

However, many participants reported a lack of knowledge regarding what type and intensity of physical activity was acceptable after stroke, which was a perceived barrier to physical activity.

"And that is the difficulty with knowing what is reasonable to do and what is silly to do. You know? Like carrying bags with shopping, how heavy is heavy when you've had a stroke and you don't want another one". 4:246

Table 3. Theoretical domains and their constructs.

Domain	Constructs
Nature of behaviour	Routine/automatic/habit Breaking habit Direct experience/past behaviour Representation of tasks Stages of change model
Skills	Skills Competence/ability/skill assessment Practice/skills development Interpersonal skills Coping strategies
Beliefs about consequences	Outcome expectancies Anticipated regret Appraisal/evaluation/review Consequences Attitudes Contingencies Reinforcement/punishment/consequences Incentives/rewards Beliefs Unrealistic optimism Salient events/sensitisation/critical incidents Characteristics of outcome expectancies—physical, social, emotional; Sanctions/rewards, proximal/distal, valued/not valued, probable/improbable, salient/not salient, perceived risk/threat
Memory, attention and decision process	Memory Attention Attention control Decision making
Knowledge	Knowledge Knowledge about condition/ scientific rationale Schemas/mind-sets/illness representations Procedural knowledge
Motivation and goals	Intention; stability of intention/ certainty of intention Goals (autonomous, controlled) Goal target/setting Goal priority Intrinsic motivation Commitment Distal and proximal goals Trans theoretical model and stages of change
Beliefs about capabilities	Self-efficacy Control—of behaviour and material and social environment Perceived competence Self-confidence/professional confidence Empowerment Self-esteem Perceived behavioural control Optimism/pessimism
Emotion	Affect Stress Anticipated regret Fear Burn-out Cognitive overload/tiredness Threat Positive/negative affect Anxiety/depression
Social influences	Social support Organisational development Leadership Team working Group conformity Organisational climate/culture Social pressure Power/hierarchy

(continued)

Table 3. Continued

Domain	Constructs
	Professional boundaries/roles Management commitment Supervision Inter-group conflict Champions Social comparisons Identity; group/social identity Organisational commitment/alienation Feedback Conflict—competing demands, conflicting roles Change management Crew resource management Negotiation Social support: personal/professional/ organisational, intra/ interpersonal, society/community Social/group norms: subjective, descriptive, injunctive norms Learning and modelling Goal/target setting Action planning Self-monitoring Goal priority Generating alternatives Feedback Moderators of intention-behaviour gap Project management Barriers and facilitators
Behavioural regulation	Identity Professional identity/boundaries/role Group/social identity Social/group norms Alienation/organisational commitment
Social/professional role and identity	Resources/material resources (availability and management) Environmental stressors Person/environment interaction Knowledge of task environment
Environmental context and resources	

Skills

“Skills” refer to the coping strategies and techniques developed by participants since their stroke, and these were the main constructs from the interviews. One facilitator described was a participant using their dogs to help them when out walking.

“put one dog at one side and one at the other on the lead”. 1:119

No coping strategy developed by a participant was a barrier to physical activity.

Social/professional role and identity

“Social role and identity” refers to both the self and professional identity (i.e. self-concept and beliefs) barriers and facilitators perceived by stroke survivors. Self-identity was the main construct and was a perceived facilitator if a participant believed they were not the type of person to be inactive before their stroke, so would not be after their stroke.

“I’m just that sort of a person. I’m not a person that can sit a lot, I’m not a person that’s sloven. I just up and go. I like to up and go. This is first class for me, my husband’s not here in the

mornings, so it’s good that I get up and do housework and sit down when I feel I’ve done enough”. 11:151

Professional role and identity (attitudes and beliefs in the context of work and profession) acted both as a perceived barrier and facilitator to physical activity. Participants reported wanting to be physically active and show they were still the same person as before their stroke. However, professional identity acted as a perceived barrier with some participants reporting feeling uncomfortable or embarrassed regarding how their stroke had changed them.

“I used to take a couple of the clients out in walking groups, although I don’t really fancy doing that myself”. 6:69

Beliefs about capabilities

“Beliefs about capabilities” refer to a participant’s feelings of their own abilities and perceptions of control over their physical activity. Self-efficacy was the mostly commonly report construct. Many participants reported they lacked control over what they were allowed to do, by their own body as well as family around them.

“People control me doing anything, somebody wants to do it for me, which is- it’s a bit daunting”. 3:190

“Well, there’s some, as I told you before, my legs, they’re the guiding factor to my capabilities shall we say, my health, and there’s some days I get really grumpy cos I’m that stiff and just things when I don’t, as though the brain’s not telling them to do anything”. 7:434

Participants with high beliefs regarding their own capabilities reported they were motivated to be physically active.

“I’m confident enough, I mean I’ll be going out this afternoon, I don’t care if it’s raining or blowing a gale or whatever and I’ll be walking down the road”. 6:239

Participants with low beliefs regarding their own capabilities reported they found it difficult to be physically active.

“My wife went off the other day for three days, I just let her go. I could have gone and seen the grandchildren out there and I just let her go because I think it would have been better. Yes I don’t know if I would have managed all that well”. 9:211

Participants reported that their beliefs regarding their own capabilities to be physically active were guided by previous health conditions prior to their stroke.

“Yes, the only thing is that I can’t walk that far. I’ve got a bad heart too. But it’s not just my stroke thing, it’s the heart damage I’ve got from the radiotherapy that causes me as much upset as that. So that’s why I can’t really do any more”. 13:142

Beliefs about consequences

“Beliefs about consequences” refer to the expectations stroke survivors feel of their actions. These commonly were expressed as fears of negative outcome expectancies towards being physically active, acting as a barrier to being physically active.

"I don't go out on my own and I don't even go to the local shops if I can avoid it on my own. Put it like that in case I fall or something silly". 10:11

"Because it's a fear. It's a fear of facing people and that, because of your disability. It's a fear that oh he won't want to speak to me, he'll laugh at me and all this". 7:667

Motivation and goals

"Motivation and goals" refers to the reasons stroke survivors believed they were physically active.

Motivation constructs were reported by participants as either intrinsic or extrinsic. Extrinsic motivators included social support, engaging in previously enjoyed activities and motivation from feedback (e.g. health professionals and pedometers).

"Just getting out in the fresh air, just, I just hate sitting in a seat all the time, you know, just getting out and taking advantage of the good weather and I enjoy going out, I'm an outdoor person sort of thing". 7:122

"Yes, yes, I mean, I can do physical exercise. I've been doing the exercises that those team people do with you. That doesn't really hurt me. It doesn't hurt me at all. And the people who take you on those courses are very, very good and very helpful. I mean, I find that they're very, very good. You go for two days a week and that goes on for about six or eight weeks. And they're very good, very good indeed. I've enjoyed going there". 3:61

Intrinsic motivation included the participant wanting to be physically active for their health and to prevent boredom.

"Well I find, I don't want to be a burden to anybody else so I've got to... I've got to get, I feel I've got to get out and do things for myself". 2:205

Some participants who reported low motivation to physical activity reported that this lack of motivation was not new and not due to their stroke. This was also linked with the participant's self identity.

"Never have been a sporty sort of type. I am not suddenly going to start now am I?" 10:179

Nature of the behaviour

"Nature of the behaviour" refers to stroke survivors' routine behaviour and this was the main construct reported by participants. For many participants their daily routine (e.g. washing, dressing, and going to the shops) was their only form of physical activity.

"Yes there must be a purpose to what one is doing, even if it's only walking to the kitchen to make a cup of tea or just to pour a cold drink or something, and being able to bring it back without spilling it". 12:634

Behaviour regulation

"Behavioural regulation" refers to the planned processes participants adopted while undertaking physical activity. The mostly commonly reported constructs were target setting and action planning which enabled participants to feel that they were able to undertake physical activity safely and confidently.

"Well I know that if I do a little, take a little more exercise, that I have to be prepared to take a little more rest the following day, and I think I build that into what I do now". 4:338

Environmental context and resources

"Environmental context and resources" refers to the lack of professional services stroke survivors reported were available to them. The most commonly reported construct was lack of resources. Participants reported feeling abandoned once leaving hospital and relied heavily on friends and family for support. This acted as a perceived barrier to physical activity.

"A very big, big thing I'd like to state is how I've been left for the whole year and not one person has come near me regarding my stroke. Nobody. I've just been left to wander. So I don't know how I'm doing. I don't know what's happening, I don't know how far on I should be, or what's wrong. Why I'm not getting. So there you are. I'm not doing well at all". 11:416

Another reported perceived barrier in this domain was a lack of transport. Participants relied heavily on friends and family for transport and reported guilt at overburdening friends and family. This led to participants not wanting to ask friends and family to take them out for extra physical activity.

"I wouldn't promise I could get out and meet a whole lot of people. I couldn't promise I'll be there, because it depends on what my husband's doing. Can he park the car, can he this, that? And it depends on him getting me there". 11:375

Social influences

"Social influences" refer to the social interactions that influenced physical activity uptake after stroke. The most commonly reported constructs were both personal and professional influences. Both of these constructs were perceived as a motivator to physical activity, while a lack of either was reported as a perceived barrier.

"What I think myself is that stroke people are often very forgotten about at home. Aren't they? Because they are disabled and if it wasn't for the family and friends I think for a lot that would be it". 13:216

Relying on friends and family for transport to simple errands and appointments elicited feelings of guilt among several participants. Participants reported guilt and unwillingness to ask friends and family to take them to extra activities such as the library or exercise classes, directly influencing participation in these activities.

"I've just been hoping to get to the library see if I can get some crochet patterns, or something, but I haven't got yet. I'm waiting on someone to take me. It's such a short distance, it's only a few yards along but I can't go myself though". 13:47

Emotion

"Emotion" refers to participants' affective reactions to taking part in physical activity. Negative affect was the most commonly reported construct and was reported as feelings of fear,

frustration, fatigue or pain and these acted as perceived barriers to physical activity.

“I did all those things and now I just don’t seem to want to do them. I’m quite happy to sit and let the world go by. But that irritates myself. I think, “You should be out doing something”. I can’t”. 3:90

“Yes, I do because you know I’m not so steady on my feet and when I’ve got quite a lot of pain I feel quite, makes me feel weepy”. 1:60

Positive affect was experienced by participants after being physically active and through encouragement from friends and family. Positive affect was a perceived motivator to physical activity.

“I think they had positive effects on my wellbeing. I felt exhilarated when I, I mean I felt tired but I still felt good about what I was doing, they gave me a self satisfaction I think really”. 4:73

Memory and attention

“Memory and attention” refers to the feelings reported by participants regarding how their memory and attention had been influenced by their stroke. Participants reported feeling unable to go out on their own because of poor memory. This caused anger and frustration and acted as a perceived barrier to physical activity.

“But my brain is poor, I know that, can’t remember things. Just stupid, you know. But I would like to do it [physical activity]”. 13:91

In summary, the most commonly reported perceived motivators were; social interaction, feeling the benefits of exercise, high self-efficacy and the necessity of routine behaviours. The most commonly reported perceived barriers were; lack of professional support on discharge from hospital and follow up, lack of transport, lack of control and negative affect.

Discussion

Our study has found several perceived barriers and facilitators to physical activity after stroke. Using the TDF, we have elicited data from all 12 domains. All perceived barriers or facilitators that emerged from the transcripts could be fitted into one of the 12 domains. “Beliefs about capabilities” was the most frequently reported domain to influence the uptake of physical activity, and included feelings of control and self-efficacy, i.e. the belief that one can successfully perform the behaviours necessary to achieve an outcome such as walking a given distance. The importance of control beliefs have also been identified in previous interview studies of stroke and other rehabilitation patients [18,19]. These studies used the Recovery Locus of Control Scale and found it predicted recovery from residual disability in stroke patients, even allowing for initial levels of disability [18,19].

Participants in our study described barriers and facilitators to physical activity that also occur in healthy populations such as a lack of energy, transportation issues [20,21] and social support from peers [22,23].

A study of barriers to physical activity in the elderly (average age; 77 years), found the three most frequently cited barriers were poor health (57.7%), lack of company (43.0%), and lack of interest (36.7%) [24]. This is different from the findings in our

participants with stroke. Our findings are consistent with previous research in stroke regarding environmental issues including transportation problems, cost of programs and a lack of knowledge of services [25]. However, lack of motivation as such was not a perceived barrier for stroke survivors’ participation in physical activity, as shown by previous studies [25–27]. By contrast, negative affect was a commonly reported barrier and was generated by feelings of fatigue, pain, frustration and fear of falling. Negative affect has not been highlighted as a potential barrier in previous stroke studies, yet fatigue and pain have been mentioned as potential barriers to physical activity [27].

Recovery from disability is an important behavioural outcome, i.e. as recovery progresses, activities and participation tend to increase [28]. Recovery involves improvement in both psychological factors (e.g. self-efficacy) as well as physical factors [28]. This interaction between physical and psychological factors is evident in Bandura’s Social Cognitive Theory and in particular the role of self-efficacy. Further it proposes that self-efficacy is an important determinant of how likely people are to act, to invest effort and to persist when there are set-backs and there is ample evidence to support this from these interviews [29].

In studies of stroke patients, self-efficacy predicts who will achieve the greatest gains in mobility, controlling for levels of actual impairment [19]. Understanding the influence that physical impairments may have on psychological factors and vice versa is essential for understanding recovery from disability. Johnston proposed a model which combines these two domains, integrating the World Health Organisation International Classification of Functioning, Disability and Health (ICF) model [13] with Bandura’s Social Cognitive model [29]. It proposes that the activity limitations are determined by health condition and impairment (from the ICF model) and by self-efficacy and beliefs about outcomes (from Social Cognitive Theory) [30]. Our results fit well with this model, identifying impairments that contributed to negative emotions, beliefs about outcomes such as embarrassment and a wide range of factors influencing self-efficacy including both physical environment (e.g. access to transport) and the availability of people to make the activity possible as well as personal confidence. Reflecting and analysing the results obtained within this qualitative study and how they fit into Johnston’s model suggests that it is essential to understand perceived barriers to physical activity behaviours not only as bodily impairments, but also as determinants of individuals’ beliefs about whether they can be physically active and whether being physically active will benefit their health. Understanding why an individual may not take part in a behaviour that should improve their health may lead to more appropriate service provision. Therefore, our study provides new stroke-specific information on barriers and motivators to physical activity, which could be included in future stroke guidelines.

Strengths

To our knowledge, our study is the only study from the UK to use qualitative methodology to explore barriers and motivators to physical activity after stroke, although another UK study used qualitative methodology to report experience of trying to resume “valued activities” [31]. The TDF ensured that we investigated a wide range of personal and environmental contextual influences and was successful in categorising participants’ responses to meaningful theoretical domains. Using open-ended questions in our interviews, we have been able to elicit rich, descriptive data. Interviews were considered more appropriate than focus groups as certain individuals may have influenced the thoughts and ideas of others [32]. We ensured data saturation using previously

published methods [16]. Participants were all approximately 1 year post stroke and had been discharged from hospital. This allowed us to understand the difficulties these participants faced after discharge and throughout their first year post stroke. At 1-year post discharge, views should be stable and representative of the longer term views of stroke survivors.

Limitations

There are limitations to this research. First, participants were recruited from a group who had previously participated in a pilot study of the feasibility, accuracy and acceptability of pedometers after stroke. Thus, participants may have been primed to think about physical activity in a way influenced by that study or may place a higher value on physical activity than those who did not participate. However, the previous study was brief, with participation on only a single occasion, carried out at least 1 year previously and is therefore unlikely have influenced the current study.

We also recognise that the barriers and facilitators elicited in these interviews are "perceived" and as such may have limited value as predictors of physical activity.

Implications for services

Our data show that stroke survivors perceive there to be a lack of services and support (e.g. GP follow-up and stroke specific exercise groups) provided to increase physical activity after stroke. As the domain "beliefs about capabilities" was evident among this group of stroke survivors, interventions which increase self-efficacy, e.g. by persuasion or by giving gradually increasing activities, might be of benefit. Stroke services should consider how each individual stroke survivor's beliefs regarding their own capabilities may influence physical activity uptake. Health care professionals and stroke survivors need to work together to determine what each stroke survivor believes they are capable of doing and what they aspire to achieve. This will give health care professionals a clearer understanding of the goals and motivations for each stroke survivor.

Implications for research

This study gives novel and important insights into the reasons why stroke survivors may feel inhibited to perform physical activity. The beliefs identified in this study will allow development of a behavioural change intervention to increase physical activity after stroke, by building on what facilitates stroke survivors to be physically active and by addressing perceived barriers.

Conclusions

There are several barriers and facilitators to physical activity perceived by stroke survivors. The most commonly reported domains were "beliefs about capabilities", "environmental context and resources" and "social influence". The most commonly reported perceived motivators were; social interaction, feeling the benefits of exercise, high self-efficacy and the necessity of routine behaviours. The most commonly reported perceived barriers were; lack of professional support on discharge from hospital and follow up, lack of transport, lack of control and negative affect.

Services must adapt to address these perceived barriers and build upon the perceived facilitators. These data have implications for health care and exercise professionals who wish to help stroke survivors to become more physically active, by allowing targeted interventions to be designed and delivered.

Acknowledgements

We would like to thank Dr Stephan Dombrowski for commenting on this article.

Declaration of interest

Funding for Fuse from the British Heart Foundation, Cancer Research UK, Economic and Social Research Council, Medical Research Council, the National Institute for Health Research, under the auspices of the UK Clinical Research Collaboration, is gratefully acknowledged. Falko Sniehotta is funded by Fuse, the Centre for Translational research in Public Health, a UKCRC Public Health Research Centre of Excellence. The study was funded by The Stroke Association through a Junior Research Fellowship for Sarah Nicholson. The authors report no conflicts of interest.

References

- Strong K, Mathers C, Bonita R. Preventing stroke: saving lives around the world. *Lancet Neurol* 2007;6:182-7.
- Johnston M, Bonetti D, Joice S, et al. Recovery from disability after stroke as a target for a behavioural intervention: results of a randomized controlled trial. *Disabil Rehabil* 2007;29:1117-27.
- Brainin M, Norrving B, Sunnerhagen KS, et al. Post stroke chronic disease management: towards improved identification and interventions for post stroke spasticity-related complications. *Int J Stroke* 2011;6:42-6.
- Field MJ, Gebruers N, Shanmuga Sundaram T, et al. Physical activity after stroke: a systematic review and meta-analysis. *ISRN Stroke* 2013;2013:Article ID 464176, 13 pages. doi:10.1155/2013/464176.
- Smith A, Saunders DS, Mead GE. Cardiorespiratory fitness after stroke: a systematic review. *Int J Stroke* 2012;7:499-510.
- Saunders DH, Greig CA, Young A, Mead GE. Association of activity limitations and lower-limb explosive extensor power in ambulatory people with stroke. *Arch Phys Med Rehabil* 2008;89:677-83.
- Brazzelli M, Saunders DH, Greig CA, Mead GE. Physical fitness training for stroke patients. *Cochrane Database Syst Rev* 2011; CD003316. DOI: 10.1002/14651858.CD003316.pub4.
- Hackam DG, Spence JD. Combining multiple approaches for the secondary prevention of vascular events after stroke: a quantitative modelling study. *Stroke* 2007;38:1881-5.
- Gordon NF, Gulanick M, Costa F, et al. Physical activity and exercise recommendations for stroke survivors. An American Heart Association Scientific Statement From the Council on Clinical Cardiology, Subcommittee on Exercise, Cardiac Rehabilitation, and Prevention; the Council on Cardiovascular Nursing; the Council on Nutrition, Physical Activity, and Metabolism; and the Stroke Council. *Circulation* 2004;109:2031-41.
- Scottish Intercollegiate Guideline Network Management of patients with stroke or TIA: assessment, investigation, immediate management and secondary prevention. A national clinical guideline; 2008.
- Becker MH, Maiman LA. Sociobehavioral determinants of compliance with health and medical care recommendations. *Med Care* 1975;13:10-24.
- Morris J, Oliver T, Kroll T, MacGillivray S. The importance of psychological and social factors in influencing the uptake and maintenance of physical activity after stroke: a structured review of the empirical literature. *Stroke Res Treat* 2012;2012. Article ID 195249, 20 pages. doi:10.1155/2012/195249.
- World Health Organization. The International Classification of Functioning, Disability and Health (ICF). Geneva: WHO; 2001. Available from: <http://www.who.int/classifications/icf/en> [last accessed 2 Dec 2013].
- Michie S, Johnston M, Abraham C, et al. Making psychological theory useful for implementing evidence based practice: a consensus approach. *Qual Saf Health Care* 2005;14:26-33.
- Carroll SL, Greig CA, Lewis SJ, et al. The use of pedometers in stroke survivors: are they feasible and how well do they detect steps? *Arch Phys Med Rehabil* 2012;93:466-70.

16. Francis JJ, Johnston M, Robertson C, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychol Health* 2010;25:1229–45.
17. Grbich C. Qualitative research in health: an introduction. London: Sage; 1999.
18. Partridge C, Johnston M. Perceived control of recovery from physical disability: measurement and prediction. *Br J Clin Psychol* 1989;28:53–9.
19. Johnston M, Morrison V, Macwalter R, Partridge C. Perceived control, coping and recovery from disability following stroke. *Psychol Health* 1999;14:181–92.
20. Booth ML, Bauman A, Owen N, Gore CJ. Physical activity preferences, preferred sources of assistance, and perceived barriers to increased activity among physically inactive Australians. *Prev Med* 1997;26:131–7.
21. Schutzer KA, Graves BS. Barriers and motivators to exercise in older adults. *Prev Med* 2004;39:1056–61.
22. Courneya KS, Plotnikoff RC, Hotz SB, Birkett NJ. Social support and the theory of planned behaviour in the exercise domain. *Am J Health Behav* 2000;24:300–8.
23. Ryan RM, Frederick CM, Lepes D, et al. Intrinsic motivation and exercise adherence. *Int J Sports Psychol* 1997;28:335–54.
24. Moschny A, Platen P, Klaaben-Mielke R, et al. Barriers to physical activity in older adults in Germany: a cross-sectional study. *Int J Behav Nutri Phys Activ* 2011;8:121–30.
25. Rimmer JH, Wang E, Smith D. Barriers associated with exercise and community access for individuals with stroke. *J Rehabil Res Dev* 2008;45:315–22.
26. Damush TM, Plue L, Bakas T, et al. Barriers and facilitators to exercise among stroke survivors. *Rehabil Nurs* 2007;32:253–60.
27. Hammel J, Jones R, Gossett A, Morgan E. Examining barriers and supports to community living and participation after a stroke from a participatory action research approach. *Top Stroke Rehabil* 2006;13:43–58.
28. Kaplan RM. Behaviour as the central outcome in health care. *Am Psychol* 1990;45:1211–20.
29. Bandura A. Self efficacy: toward a unifying theory of behavioural change. *Psychol Rev* 1977;84:191–215.
30. Johnston M. Models of disability. *Physiothera Theor Pract* 1996;12:131–41.
31. Robison J, Wiles R, Ellis-Hill C, et al. Resuming previously valued activities post-stroke: who or what helps? *Disabil Rehabil* 2009;31:1555–66.
32. Morgan DL. Focus groups as qualitative research. 2nd ed. USA: SAGE publication; 1997.

Appendix 1. Interview schedule

Objective: (For reference only)

The purpose of this interview is to look closer at the barriers and motivators that patients who have suffered strokes feel once they have been discharged from hospital. We hope to eventually develop a behavioural change intervention to help and encourage stroke patients back into exercise once discharged from hospital. The intervention would be designed to facilitate behaviour change by enhancing self-regulatory skills and increasing environmental supports rather than enhancing motivation which is already high. Investigating the barriers and motivators to physical activity after stroke is essential before we can develop such an intervention.

This interview will be voice recorded, to ensure I have a full record of all that is discussed and to ensure I miss nothing.

- (1) To determine the motivators and barriers towards physical activity after stroke.
- (2) To investigate patients' views on the best ways to promote and encourage physical activity post stroke.
- (3) To explore the views of patients on acceptability of using a pedometer as part of a motivational aid to increase activity.
- (4) To explore possible barriers and motivators to participating in a trial to increase activity after stroke with the aid of a pedometer.

Introduction:

- Thank you for agreeing to take part in this interview
- Introduce self, met when patient was in hospital.
- Interview will last no longer than 1 h.
- Explain purpose of research:

I would like to talk to you about physical activity and exercise within the first year after stroke. By this I mean looking at any bodily movement that uses up energy.

I would also like to understand what encourages you to be more active and what prevents you from exercising.

This information will allow us to develop a better method of assisting patients to return to exercising after a stroke. This will include stroke patients being given a structured guidance on how to exercise, and we will then compare these patients to those who have received normal care but not the new programme.

- If at any point, you would like to take a break, or stop the interview just let me know.
- If there are any questions you do not wish to answer just let me know.
- Reassure re: confidentiality- nothing you say will be linked to your name. We shall be voice recording the interview but will use a unique number to identify you.
- It is important of interviewee saying what they think; there are no right or wrong answers, all opinions valid and helpful.
- Check interviewee is comfortable with interview format. Any questions?

1. General background and experiences after stroke:

Initially wish to obtain a little information about life since you have been discharged from hospital (*keep to 10 mins*).

- Tell me a little bit about your home life . . .
 - Who do you live with/family
 - Employment
 - How long since discharge? Since we last met have you been back in hospital?
 - Hobbies/physical activity during a typical week
 - What do you find difficult to do since coming home from hospital?
 - Are there aspects of the house that if changed would make things easier for you?
 - Need extra support from family: cooking, cleaning, shopping.

2. Factors Associated with Physical Activity

- What physical activities do you like doing?
 - (explore hobbies, walking, exercise, sports, community, clubs and groups, learning/training)

- What is it you enjoy about these activities?
 Do you find it easy to do the activities you enjoy? What makes it easy?
 How do you get there?
 What exactly do at clubs/group?
 Always do exactly the same?
- Could you talk me through your activities in a typical day? {walking, sitting, exercising}
 Is your routine similar every day or are their days your more or less active?
 Is this the same amount of activity you did before your stroke?
 What makes it difficult to do the activities that you enjoy?
 - What is encouraging you to be physically active in the first year since your stroke?
- (PROMTS)
- 1 BEHAVIOURAL ATTITUDE: *you feel happier, you feel physically better, you will lose (or maintain) your weight, you think it will benefit your health, because it will prevent future illness including stroke, because you will meet (new) people, because you will learn new skills, enjoy keeping fit.*
- 2 SUBJECTIVE NORMS: *Because other people think it's a good idea – your doctors, your family, your friends*
- 3 PERCEIVED BEHAVIOURAL CONTROL: *Because you feel confident that you can do this – you have the ability, you can easily get there, you have the resources and support you need to do it, you can manage to sort out any difficulties about doing it*
- Have these things always encouraged you to be active or has anything changed since you had your stroke?
 Do you still get as much (or more) good things from being active?
 Do you still get as much (or more) encouragement from other people?
 Do you still feel as confident that you can manage to do these activities?
 - Are there certain people or resources that enable you to be physically active?
 - Are there activities that you are less confident about doing since you had your stroke?
 Has anything helped boost your confidence? {looking at self efficacy}?
 - How confident are you that will be able to increase your walking over the first year post stroke
 1 2 3 4 5
 - I intend or plan to walk more over the next year?
 Strongly Agree, Agree, Neither agree or disagree, Disagree,
 Strongly Disagree
- (Compare with previous) You may be interested to know that you scores have ?? from last pilot study. Do you know why this may be?
- How easy is it for you to partake in physical activity?
 - What activities have you done in the past but are no longer involved with, due to your stroke?
 - What is preventing you from doing these activities in the first year since your stroke?
 1. BEHAVIOUR ATTITUDE: *consequences pain, discomfort, don't enjoy it, not interested in exercise,*
 2. SUBJECTIVE NORM: *other people think you shouldn't doctor, nurses, family*
 3. PERCEIVED CONTROL: *control/self-efficacy(fear, ill health, time restraints, confidence, previous injuries or disabilities, too tired depression, lack of practical social support,) lack of motivation, unwillingness, lack of a clear plan or routine.*
 - What strategies do you use to overcome these barriers you have mentioned?
 How in control do you feel about being able to be active and/or take exercise?
 Are there things you do that help boost your feeling of control over being active or taking exercise?
 What reduces your feeling of control over being active of taking exercise?
 - Do you know of any local exercise classes designed for people who have had strokes within your area?
 How do you/could you find out about local activities/groups?
 Are you happy with the exercise classes available to you?
3. Views on how participants feel an intervention could assist them in becoming more physically active
- How important do you feel exercise and physical activity is to patients after stroke?
 For the general population, why do you think activity levels are low after stroke?
 - Tell me what you think is the best way to encourage people to be physically active after a stroke?
(explore, other people (in the home, or friends or other people who have had strokes) being active, encouragement from other people including doctors and nurses, attractive place/places nearby to do activities, stroke specific group classes, individual interventions, structured physiotherapy classes, only advice on discharge, follow up from stroke outreach services, pedometers, telephone intervention, leaflets on how to exercise)
 - We tried out a pedometer with you when you were in hospital:
 If you had been discharged with a pedometer do you think this would have made a difference to your levels of physical activity?
 Tell me why you think that?
 Would it be easy for you to fit a pedometer into daily life?
 Would you feel comfortable doing this?
 Do you feel any potential draw backs to using pedometers?
 What would encourage people to wear and use pedometers?
 - How would you feel about participating in a study where you would use a pedometer as encouragement to increase physical activity?
 What draw back can you see from participating in such a study?
 Would you be keen for help to increase you exercise once you had been discharged from hospital?
 Would having weekly step goals keep you motivated to increase your walking?
 What would encourage you to partake in this?
 What would prevent you from taking part in this?
- The research is likely to take place the first 3 months on discharge from hospital. Within these 3 months you would be given a pedometer and weekly step targets to adhere to. We plan to deliver a behavioural change intervention. This means we shall be in regular contact with you giving advice and encouragement throughout the intervention, to help you to increase your physical activity and become more active. I have a couple of different scenarios and would like you to give me your opinion on which you would prefer:
- How would you prefer advice and encouragement to be delivered? (rank 1–5)

Individual meetings

Group meetings

Internet

Telephone

Letter

- Can you tell me why you think this?
- How often should advice be delivered?
Once every 2 weeks, once a week, more than once a week?
- Can you tell me why you think this?
- Would you like weekly step targets to try and adhere to, or just try and increase you own steps?
Targets No targets
- Can you tell me why you think this?

Conclusions:

- Interview concluded
- Thank you for taking part
- Any thing not discussed you want to tell me related to the areas we have talked about which we can return to now?
- Any questions or comments about anything discussed?

4.4. Discussion

To use the data from the qualitative study to be able to go and develop the behaviour change intervention it was important to determine what TDF domains were deemed to be important to stroke survivors. The concepts of the TDF proved to be relevant to stroke survivors as the 13 interview transcripts provided data from all domains. In addition all perceived barriers and facilitators emerging from the transcripts were captured by at least one of the 12 domains. The most commonly reported domains were “beliefs about capabilities”, “environmental context and resources”, and “social influences”, whilst the least commonly reported domains were “skills” and “memory and attention”. The frequency of each domain reported throughout the 13 interviews is detailed in figure four.

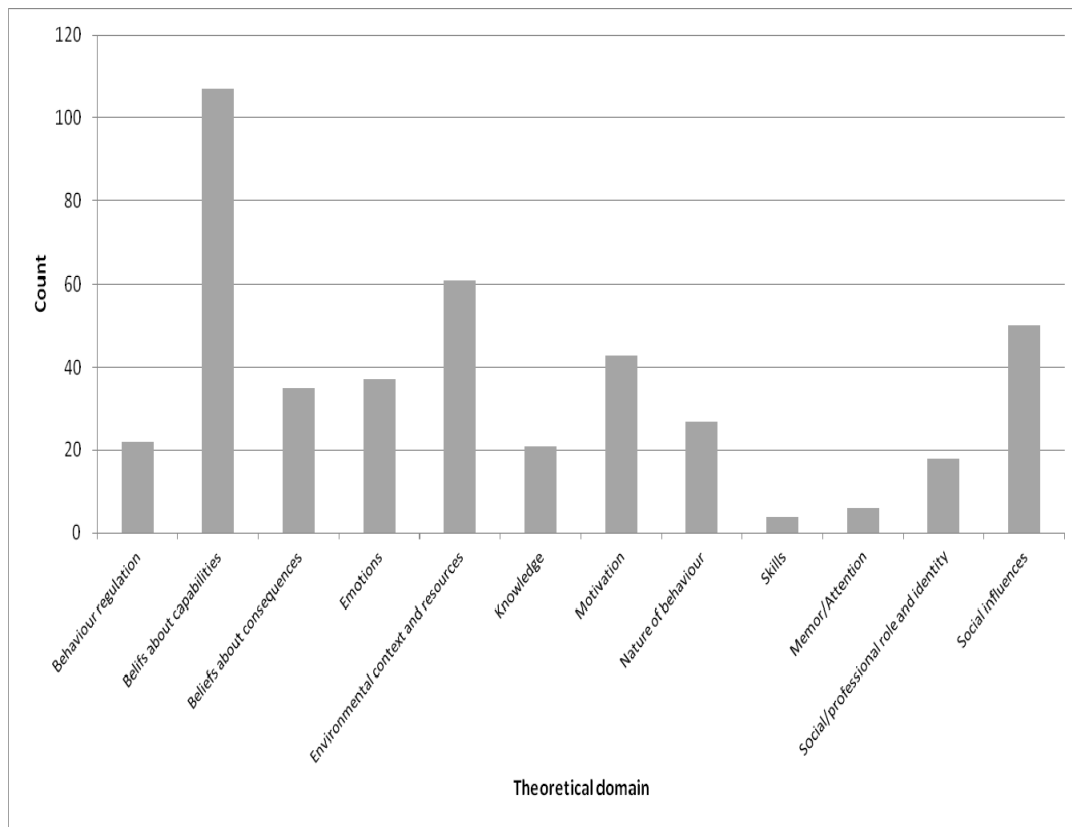


Figure 4: Frequency of the reported barriers and facilitators in each TDF domain

Count is the number of times that the domain was mentioned throughout the 13 interviews

As the overall aim of this PhD was to develop a behaviour change intervention with the help of the TDF, it was necessary to code the transcripts accordingly. The use of content analysis is sometimes seen as a negative in qualitative research, as it can restrict the meaning of the data. However, it was viewed as appropriate for this research to allow the development of the behaviour change intervention. The TDF ensures that a wide range of personal and environmental contextual influences to physical activity were examined and allowed categorisation of participants' responses into meaningful theoretical domains (Michie et al., 2008). Allowing for the development of the behaviour change intervention throughout identification of BCTs aligned to the TDF.

4.5. Conclusions

This qualitative study builds on the previous research conducted in the systematic review on the perceived barriers and facilitators to physical activity after stroke. The data obtained from this qualitative study were incorporated into the development of a behaviour change intervention to increase and encourage physical activity after stroke (reported in chapter seven). This study gives novel and important insight into the reasons why stroke survivors may not take part in physical activity. Tackling the issues that are raised by the participants of this study will allow further research to be developed that is patient centred and more likely to target the needs of stroke survivors.

This work has shown beliefs about capabilities and environmental factors are essential components of the uptake of physical activity. More over the lack of

services stroke survivors feel are available to them may prevent participation in physical activity. The study found that 7/13 (54%) of the participants lived alone, which may further highlight the importance of increasing the need of professional and social support both inside and outside the home. The take home messages from this qualitative study are detailed in table three.

Table 3: Qualitative study summary

Qualitative Study Summary
<ul style="list-style-type: none"> • Qualitative interviews elicit highly descriptive and personal information from participants, which enables very detailed accounts of physical activity influences. • Data was elicited from all 12 domains of the TDF • The most commonly reported domains were “beliefs about capabilities”, “environmental context and resources”, and “social influences”, • The least commonly reported domains were “skills” and “memory and attention”. • The most commonly reported perceived facilitators were; social interaction, beliefs of the benefits of exercise, high self-efficacy and the necessity to perform routine behaviours. • The most commonly reported perceived barriers were; lack of professional support on discharge from hospital and follow up, transport issues to structured classes/ interventions, lack of control and negative affect.

CHAPTER 5 Quantitative analysis of the perceived barriers, facilitators, self-efficacy and intention to physical activity after stroke

5.1. Introduction

Both the systematic review and the qualitative study confirmed that the perceived barriers and facilitators to physical activity after stroke can play an important role in the uptake of physical activity. The systematic review highlighted that negative affect can act as a barrier to physical activity. The qualitative study also found negative affect was a barrier to physical activity, while positive beliefs about capability acted as a facilitator to physical activity. Therefore, both of these highlighted the importance of self-efficacy towards the uptake of physical activity. Evidence suggests that the extent of self-efficacy towards walking after stroke can be a long term predictor of physical activity (Bonetti and Johnston, 2008). Therefore close examination of self-efficacy to physical activity after stroke may provide useful information for the development of the behaviour change intervention. This study has been published by the 'Journal of the Royal College of Physicians Edinburgh' (Nicholson et al., 2017). All the recruitment, collection of data, carrying out the walking tests with participants, analysis of participant gait and drafting of the manuscript was performed by SN. JS also performed gait analysis with SN. Statistical analyses were performed by SJL. All authors provided comments of the drafts of the manuscript prior to publication.

5.2. Background

Evidence suggests that the extent of self-efficacy towards walking after stroke can be a long term predictor of physical activity (Bonetti and Johnston, 2008). The previous systematic review showed there was a lack of literature on perceived barriers and facilitators to physical activity after stroke, and most of this literature was at least six months post discharge from hospital. The qualitative study, detailed in the previous chapter, also highlighted stroke survivors' perceived barriers and facilitators to physical activity at one year post discharge from hospital. Therefore the current study would investigate what stroke survivors perceive are barriers and facilitators at discharge, investigate the role of self-efficacy and intention to be physically active and (in combination with the qualitative study and systematic review) be able to tailor suitable behavioural change interventions accordingly.

Therefore, the aim of the quantitative data analysis was to explore the barriers and facilitators perceived by stroke survivors, including self-efficacy and intention to increasing physical activity upon discharge from hospital after acute stroke.

5.3. Published paper

J R Coll Physicians Edinb 2017; 47: 231–6 | doi: 10.4997/JRCPE.2017.304

PAPER

Quantitative data analysis of perceived barriers and motivators to physical activity in stroke survivors

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Abstract

Background Levels of physical activity after stroke are low, despite multiple health benefits. We explored stroke survivors' perceived barriers, motivators, self-efficacy and intention to physical activity.

Methods Fifty independently mobile stroke survivors were recruited prior to hospital discharge. Participants rated nine possible motivators and four possible barriers based on the Mutrie Scale, as having 'no influence', 'some influence' or 'a major influence' on physical activity. Participants also rated their self-efficacy and intention to increasing walking.

Results The most common motivator was 'physical activity is good for health' [34 (68%)]. The most common barrier was 'feeling too tired' [24 (48%)]. Intention and self-efficacy were high. Self-efficacy was graded as either 4 or 5 (highly confident) on a five-point scale by [34 (68%)] participants, while 42 (84%) 'strongly agreed' or 'agreed' that they intended to increase their walking.

Conclusion Participants felt capable of increasing physical activity but fatigue was often perceived as a barrier to physical activity. This needs to be considered when encouraging stroke survivors to be more active.

Keywords: barrier, motivator, physical activity, self-efficacy, stroke

Declaration of interests: No conflict of interests declared

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Introduction

Stroke affects 17 million individuals annually and is the largest cause of disability globally.¹ In the UK over a third of stroke survivors will be dependent on others; of those, one in five will be cared for by a family member.²

Physical activity is defined as 'any bodily movement produced by skeletal muscles that results in energy expenditure'.³ Physical fitness is defined as 'a set of attributes that people have or achieve that relates to the ability to perform physical activity'.³ After stroke, both physical activity^{4,5} and physical fitness⁶ are low, and impaired physical fitness is associated with activity limitations.⁶ Low physical activity and physical fitness are risk factors for a first ever stroke.⁷ Risk modelling studies suggest that the risk of repeated stroke could be reduced by approximately 20% if physical activity is undertaken.⁸ Even after minor stroke, physical

activity is below what is observed in healthy older adults and other patient populations.⁹ Several randomised controlled trials have demonstrated the benefits of physical activity after stroke in increasing physical function and improving fitness.^{10–13} A recently updated Cochrane Review showed cardiorespiratory training, including walking, reduces disability, dependence on others during ambulation and improves walking speed in stroke survivors.⁶ Consequently, physical activity is recommended for stroke survivors in several national clinical guidelines, including guidelines from the American Heart Association and Scottish Intercollegiate Guidelines Network.^{14,15} However, not all stroke survivors wish to participate in structured exercise programmes¹¹ and fewer than 30% of stroke survivors will undertake the minimum recommendations of physical activity.¹⁶ Therefore, approaches to facilitate uptake and long-term maintenance of physical activity after stroke are required.

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A recent systematic review detailed interventions that promote long-term participation in physical activity after stroke.¹⁷ This review investigated measures including frequency, duration and intensity of physical activity at three months or longer in community-dwelling stroke survivors.¹⁷ Results showed tailored counselling alone or with tailored supervised exercise improved long-term physical activity participation and functional exercise capacity after stroke more than tailored supervised exercise with general advice only.¹⁷ To determine the content of 'tailored counselling' for stroke survivors it is essential to understand what prevents physical activity uptake after stroke. A systematic review of the perceived barriers and motivators to physical activity post stroke found this to be an understudied area of research.¹⁸ Only six papers were included in this review, providing information on 174 stroke survivors who were at least six months post stroke. The most commonly reported perceived motivator to physical activity was the possibility of meeting other people with stroke which provided both psychological and social support for participants. The most commonly reported barriers were environmental (access/transport/costs), health problems or stroke-related impairments discouraging activity, embarrassment and fear of recurrent strokes.¹⁸ The perceived barriers identified in this systematic review included those likely to reduce self-efficacy, i.e. individuals' beliefs that they can engage in the activity. In social cognitive theory,¹⁹ control beliefs are conceptualised as self-efficacy, defined in terms of beliefs about capabilities to execute behaviours. Evidence suggests that the extent of self-efficacy towards walking after stroke can be a long term predictor of physical activity.²⁰ In studies of stroke patients, self-efficacy predicts who will show the greatest improvements in mobility, controlling for actual severity of physical impairment.^{21,22} Therefore self-efficacy may play an important role in enabling or preventing stroke survivors performing physical activity.

The aim of the current study was to explore stroke survivors' perceived barriers and motivators to increasing physical activity upon discharge from hospital after acute stroke. The study also aimed to determine self-efficacy and intention to increase walking upon discharge from hospital. Within group comparisons were performed to determine if two walk tests influenced self-efficacy and intention to walk after discharge from hospital. This study was part of a programme of research with the overarching aim of developing a behaviour change intervention to increase physical activity after stroke.

Methods

Stroke survivors were recruited from hospital acute stroke units to a study that assessed the feasibility and acceptability of pedometers in detecting step counts.²³ As part of this study, participants were asked about their perceived barriers, motivators, self-efficacy and intention towards physical activity. This current paper reports the data on barriers, motivators, self-efficacy and intention to physical activity. Data on the validity and feasibility of pedometers have been reported previously.²³ Ethical approval for the study was obtained from South East Scotland Research Ethics Committee 01.

Participants

We recruited 50 participants admitted with an acute stroke (first-ever or recurrent) who were ready for discharge from six stroke units in Edinburgh and the Lothians (two acute, three rehabilitation and one mixed rehabilitation/acute unit). Potential participants were identified in consultation with clinical teams, between 27/10/2009 and 15/04/2010.

Patients were included in the study if they were independently ambulatory, with or without walking aids, and able to give informed consent. Patients were excluded if they were medically unstable (as identified by Mead et al.¹¹) and therefore unable to perform the walking tests safely.

Data on stroke subtype were extracted from the case notes of each participant. A Barthel Score,²⁴ Rankin Score,²⁵ participant age at time of stroke, the presence of neurological deficits (including hemiparesis, visual field deficits and speech problems) and the time since stroke for each participant were obtained through scrutiny of notes and discussions between the research assistant and the clinical teams.

The walks

Participants completed two walks (a 6-minute walk test and a 'short walk') with three pedometers attached to varying locations. These walks were conducted to determine the accuracy of the pedometers, and this has been previously described in detail.²³

Barriers and motivators to physical activity

After completing the walking tests, participants were asked to rate four possible barriers and nine possible motivating factors to participating in physical activity after stroke. These potential motivators were based on the Mutrie Scale.²⁶ This has previously successfully been used to rate barriers and motivators to physical activity in older individuals.²⁷ The measure was chosen due to its simplicity in measuring perceived barriers and motivators to physical activity. Participants rated the potential barriers and motivators as either 'no influence,' 'some influence' or a 'major influence' to participating in physical activity post stroke.

The motivating factors participants were asked to rate were: 'If the doctor told me to exercise'; 'The belief that exercise is good for my health'; 'To become fitter'; 'To feel in good shape mentally'; 'To help clear my head'; 'To get rid of tension and stress'; 'To feel in good shape physically'; 'To relax and forget about my cares'; 'To improve or learn new skills'.

The possible barriers to physical activity were: 'Poor health'; 'Feeling too tired'; 'Fear of getting injured or damaging my health'; 'Any injuries or disabilities I already have'.

Self-efficacy and intention to walking

To determine participants' self-efficacy and intention to

walking at the point of discharge from hospital, they were asked the following two statements and rated their answers to each statement on two separate 5-point rating scales.

To determine self-efficacy to walking participants were asked 'How confident are you that you will be able to increase your walking over the next month? Participants answered this question on a scale of 1–5, where 5 was the most confident and 1 the least confident at being able to increase walking over the next month.

To determine intention to walking participants were asked how much they agreed with the statement 'I intend or plan to walk more over the next month'. The intention statement was graded 1–5 with 1 indicating the participant 'strongly disagreed' with the statement and 5 indicating the participant 'strongly agreed'.

To determine if the walks influenced participants' self-efficacy and intention, participants were randomised into two groups using computer-generated random numbers placed in opaque envelopes. Those randomised to group 1 were asked self-efficacy and intention questions both before and after the two walks, while those randomised to group 2 were asked these questions only after the two walks were completed. This was to explore whether the experience of performing a challenging walking test altered a) self-efficacy about walking and b) intention to increase walking. The inclusion of group 2 would also allow comparison of after data from the two groups, to determine if those who were primed to think about self-efficacy and intention prior to the walk (group 1) were more likely to be confident in their ability to walk more when home from hospital.

Results

Table 1 gives the demographics for the study participants. In total, 67 stroke survivors were approached to take part in the study, of whom 17 declined. Fifty participants [(29/50) 58% female] undertook the walking tests, of whom 47/50 could be interviewed on barriers and motivators to physical activity (two participants with expressive dysphasia and one with profound deafness could not answer the questions). Forty-nine participants were able to answer the self-efficacy and intention questions. Participant average age was 72.4 yrs (standard deviation: 12.3 yrs); 46 participants had had an ischaemic stroke. The median time since stroke for participants participating in the study was 12.5 days (interquartile range: 6.25–34 days).

Motivators

Figures 1 and 2 show the responses from the 47 participants who were interviewed on perceived barriers and motivators to physical activity after stroke. The belief that 'exercise is good for your health' was the perceived motivator most commonly reported as a 'major influence' to encourage physical activity [33/47 (70.2%)]. 'To become fitter' [31/47 (66%)], 'to feel in good shape mentally' [27/47 (57%)] and

Table 1 Participant demographics

Demographic variables	No. of patients (%)
Total	50 (100)
Gender:	
Male	21 (42)
Female	29 (58)
Age (mean, SD)	72.4 (SD 12.3)
Pathology:	
Haemorrhagic	4 (8)
Ischaemic	46 (92)
Oxford Community Stroke Project Classification:	
• Total Anterior Circulation Stroke	5 (10)
• Partial Anterior Circulation Stroke	26 (51)
• Lacunar stroke syndrome	8 (16)
• Posterior Circulation Stroke	5 (10)
	6 unknown
Side of brain lesion:	
Left	25 (49)
Right	24 (47)
Both	1 (2)
Time since stroke (days), (median, IQR)	12.5, 6.25–34
Barthel Score, (median, IQR)	100, 90–100
Rankin Score, (median, IQR)	2, 1–3

'to feel in good shape physically' [26/47 (55%)] were the next most commonly perceived 'major influence' motivators to encourage physical activity. The motivators that were most commonly reported as 'no influence' to the uptake of physical activity included 'to improve/learn new skills' [23/47 (49%)], 'to relax and forget about your cares' [16/47 (34%)] and 'to get rid of stress or tension' [16/47 (34%)].

Barriers

'Poor health' [23/47 (49%)] was the most commonly reported barrier as a 'major influence' on preventing the uptake of physical activity. 'Poor health' was followed closely by the perceived barrier of feeling 'too tired' [21/47 (45%)]. Participants fearing they 'might get injured or damage health' while taking part in physical activity was only reported by 10/47 (21%) participants as a 'major influence' in preventing physical activity. Furthermore, 31/47 (66%) reported 'might get injured or damage health' as 'no influence' on preventing their uptake of physical activity. Similarly only 7/47 (15%) reported 'an injury or disability' would have a 'major influence' on preventing them from being physically active, while 26/47 (55%) said it would have 'no influence'.

Self-efficacy and Intention

Table 2 shows the responses to the self-efficacy and intention

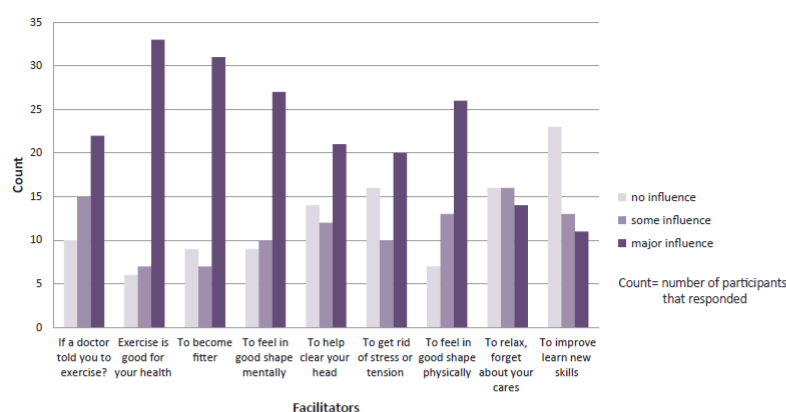


Figure 1 Perceived facilitators to physical activity

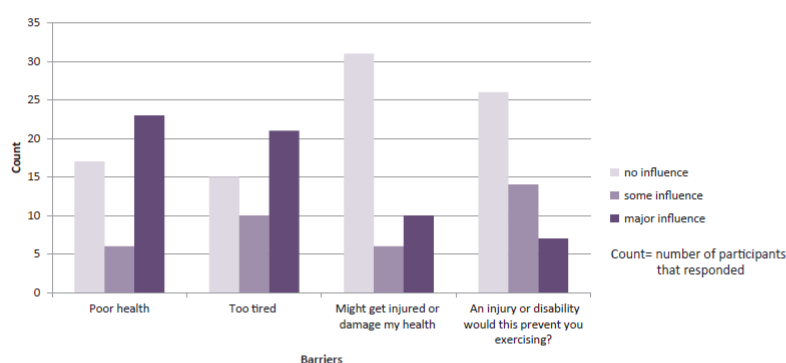


Figure 2 Perceived barriers to physical activity

statements. Data for one participant were not recorded due to their expressive dysphasia. Both self-efficacy and intention were high in both groups of participants. Three participants reported they did not intend to walk more in the next month, and only marked themselves at the lowest point on the self-efficacy scale. Mann-Whitney U tests were performed to compare the 'after' answers in the two groups; there was no significant difference between scores for self-efficacy ($p = 0.59$) or intention ($p = 0.84$). Similarly, no significant difference was found between the 'before' and 'after' scores for self-efficacy ($p = 0.77$) or intention ($p = 0.16$) for group 1. There was also no significant difference between the 'before' scores for group 1 and the 'after' scores for group 2; self-efficacy ($p = 0.78$) or intention ($p = 0.64$).

Discussion

Key findings

Results show that both self-efficacy and intention to physical activity were high prior to discharge from hospital, and these were not affected by performing the walking tests. Participants stated that they were confident about increasing their physical activity, and intended to do so upon discharge from hospital.

The belief that 'exercise is good for your health' was the perceived motivator most commonly reported as a 'major

influence' to encourage physical activity [33/47 (70.2%)]. 'To become fitter' [31/47 (66%)], 'to feel in good shape mentally' [27/47 (57%)] and 'to feel in good shape physically' [26/47 (55%)] were the next most commonly perceived 'major influence' motivators. 'Poor health' [23/47 (49%)] was the most commonly reported barrier as a 'major influence' on preventing the uptake of physical activity. Poor health was also found to be a major barrier in community dwelling older adults [28]. Feeling 'too tired' [21/47 (45%)] was also a commonly reported barrier. Fatigue is a common complication post stroke; a systematic review of longitudinal studies demonstrated that the frequency of fatigue is between 35%–92% and can be persistent symptom for at least 36 months after stroke.²⁹ A recent systematic review including 19 papers (2,072 stroke survivors) reported that fatigue may be an important clinical determinant of a progressively disabling pattern of reduced physical activity and/or physical fitness.³⁰

Our results show stroke survivors appear to be highly motivated to increase their physical activity on discharge from hospital. However, we know from previous studies that fewer than 30% of stroke survivors will undertake the minimum recommendations of physical activity.¹⁶ The main barriers identified from our study included those likely to reduce self-efficacy. In social cognitive theory¹⁹ control beliefs are conceptualised as self-efficacy. A prospective cohort study within a randomised controlled trial of stroke survivors has

Table 2 Self-efficacy and intention statements

	Self-efficacy 'How confident are you that you will be able to increase your walking over the next month?'				Intention 'I intend or plan to walk more over the next month?'		
	Group 1		Group 2		Group 1		Group 2
	Before n (%)	After n (%)	After n (%)		Before n (%)	After n (%)	After n (%)
Not answered	1 (4)	1 (4)	1 (4)	Not answered	1 (4)	1 (4)	1 (4)
1 (least confident)	0	0	1 (4)	1 (strongly disagree)	0	0	0
2	2 (8)	0	2 (8)	2 (disagree)	0	1 (4)	2 (8)
3	6 (24)	6 (24)	5 (20)	3 (neither agree nor disagree)	2 (8)	2 (8)	1 (4)
4	7 (28)	10 (40)	8 (32)	4 (agree)	13 (52)	14 (56)	13 (52)
5 (most confident)	9 (36)	8 (32)	8 (32)	5 (strongly agree)	9 (36)	7 (28)	8 (32)
Total	25 (100)	25 (100)	25 (100)		25 (100)	25 (100)	25 (100)
Mean (SD)	3.96 (0.99)	4.08 (0.76)	3.83 (1.13)		4.29 (0.62)	4.13 (0.74)	4.13 (0.85)

shown the importance of perceived behavioural control to increasing physical activity post stroke.^{20,31} The cohort study showed walking limitations and walking recovery after stroke was predicted by stroke survivors' perceived behaviour control.²⁰ We have also shown similar results in a qualitative study where we found control beliefs to be a major barrier to physical activity.³² However, this study was conducted with participants approximately 1 year post discharge from hospital [median 345, IQR = 316–366], so beliefs may have altered.³²

Limitations of the study

There are potential limitations to this study. We report on data collected as part of a larger study of the feasibility and acceptability of pedometers to increase physical activity after stroke, which may have introduced some bias as participants had selected to take part in a study about encouraging physical activity. A further limitation was that responses to the questions about self-efficacy and intention to increasing walking could be influenced by the fact that participants were in hospital at the time of the assessment. We know that people in hospital after a stroke spend very little time walking.³³ So participants may have reflected on how much walking they were doing in hospital and therefore felt confident about increasing their walking on returning home. However, stroke is a serious life-changing event for many and returning home from hospital can be daunting. Knowing stroke survivors have high self-efficacy and intention to increasing walking prior to discharge, yet fewer than 30%

meet activity guidelines, shows this may be a key time to implement interventions aimed at increasing physical activity after stroke.

Implications for future research

To our knowledge this is the first study that has interviewed stroke survivors prior to discharge from hospital to determine their self-efficacy, intention, barriers and motivators to physical activity. Most previous studies have recruited stroke survivors approximately 1 year after discharge from hospital. This current study has given valuable insight into the beliefs of stroke survivors prior to discharge. In addition, the study has raised important questions as to why stroke survivors are not meeting physical activity recommendations, even though they appear highly motivated to do so. This study will help to design a behaviour change intervention to increase physical activity after stroke by helping to develop the 'tailored counselling' deemed an essential component of this intervention.¹⁷ Ideally this tailored counselling will be able to maintain this high self-efficacy and intention by tackling the perceived barriers stroke survivors feel towards participation in physical activity.

Fatigue was a significant barrier to physical activity, and we know that this is a major issue for stroke survivors.³⁴ There is limited evidence about the relationship between physical activity, physical fitness and fatigue,³⁵ and this study lends weight to the need for further research in this area.

Conclusions

Self-efficacy and intention to physical activity were high prior to discharge from hospital, yet there are several barriers and motivators to physical activity perceived by stroke survivors. The most commonly reported motivators were 'exercise is good for your health' and 'to improve fitness' and the most commonly perceived barriers were 'having poor health' and 'feeling too tired'. These data have implications for healthcare and exercise professionals who wish to help

stroke survivors become more physically active, by allowing targeted interventions to be designed and delivered. It is essential to ensure exercise beliefs and preferences are taken into account when advising stroke survivors to be more physically active. Stroke services need to establish community-based exercise programmes for stroke survivors. These programmes will ideally target the first year post discharge from hospital to help maintain high self-efficacy and intention to walking and, in turn, increase physical activity after stroke. ①

References

- Feigin VL, Forouzanfar MH, Krishnamurthi R et al. Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet* 2014; 383: 245-54.
- Stroke Association. *State of the Nation: stroke statistics*. 2017. https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2017_final_1.pdf
- Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise and physical fitness: Definitions and distinctions for health-related research. *Public Health Rep* 1985; 100: 126-31.
- Bernhardt J, Dewey H, Thrift A et al. Inactive and alone: physical activity within the first 14 days of acute stroke unit care. *Stroke* 2004; 35: 1005-9.
- Rand D, Eng JJ, Tang PF et al. How active are people with stroke?: use of accelerometers to assess physical activity. *Stroke* 2009; 40: 163-8.
- Saunders DH, Sanderson M, Hayes S et al. Physical fitness training for stroke patients. *Cochrane Database Syst Rev* 2016; 3: CD003316.
- Lee CD, Folsom AR, Blair SN. Physical activity and stroke risk: a meta-analysis. *Stroke* 2003; 34: 2475-81.
- Hackam DG, Spence JD. Combining multiple approaches for the secondary prevention of vascular events after stroke: a quantitative modelling study. *Stroke* 2007; 38: 1881-5.
- Field MJ, Gebruers N, Sundaram TS et al. Physical activity after stroke: a systematic review and meta-analysis. *ISRN Stroke* 2013: Article ID 464176.
- Cramp MC, Greenwood RJ, Gill M, et al. Low intensity strength training for ambulatory stroke patients. *Disabil Rehabil* 2006; 28: 883-9.
- Mead GE, Greig CA, Cunningham I, et al. Stroke: a randomized trial of exercise or relaxation. *J Am Geriatr Soc* 2007; 55: 892-9.
- Macko RF, Ivey FM, Forrester LW et al. Treadmill exercise rehabilitation improves ambulatory function and cardiovascular fitness in patients with chronic stroke: a randomized, controlled trial. *Stroke* 2005; 36: 2206-11.
- Mudge S, Barber PA, Stott NS. Circuit-based rehabilitation improves gait endurance but not usual walking activity in chronic stroke: a randomized controlled trial. *Arch Phys Med Rehabil* 2009; 90: 1989-96.
- Billinger SA, Arena R, Bernhardt J et al. Physical Activity and Exercise Recommendations for Stroke Survivors: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association. *Stroke* 2014; 45: 2532-53.
- SIGN. *Management of patients with stroke or TIA: assessment, investigation, immediate management and secondary prevention*. SIGN Guideline 108. December 2008.
- Shaughnessy M, Resnick BM. Using theory to develop an exercise intervention for patients post stroke. *Top Stroke Rehabil* 2009; 16: 140-6.
- Morris JH, Macgillivray S, McFarlane S. Interventions to promote long-term participation in physical activity after stroke: a systematic review of the literature. *Arch Phys Med Rehabil* 2014; 95: 956-67.
- Nicholson S, Sniehotta FF, van Wijck F et al. A systematic review of perceived barriers and motivators to physical activity after stroke. *Int J Stroke* 2013; 8: 357-64.
- Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. *Psychol Rev* 1977; 84: 191-215.
- Bonetti D, Johnston M. Perceived control predicting the recovery of individual-specific walking behaviours following stroke: testing psychological models and constructs. *Br J Health Psychol* 2008; 13(Pt 3): 463-78.
- Johnston M, Morrison V, Macwalter R et al. Perceived control, coping and recovery from disability following stroke. *Psychology and Health* 1999; 14: 181-92.
- Hellström K, Lindmark B, Wahlberg B et al. Self-efficacy in relation to impairments and activities of daily living disability in elderly patients with stroke: a prospective investigation. *J Rehabil Med* 2003; 35: 202-7.
- Carroll SL, Greig CA, Lewis SJ et al. The use of pedometers in stroke survivors: are they feasible and how well do they detect steps? *Arch Phys Med Rehabil* 2012; 93: 466-70.
- Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. *Md State Med J* 1965; 14: 61-5.
- Van Swieten J, Koudstaal PJ, Visser MC et al. Interobserver agreement for the assessment of handicap in stroke patients. *Stroke* 1988; 19: 604-7.
- Mutrie N, Blamey A, Davidson R. *Class based and home based activities for older people*. Scottish Sports Council Report No 32: Edinburgh 1993.
- Payne A, Greig C, Young A et al. Views of stroke patients on physical fitness training. *Age Ageing* 2001; 30: 429.
- Gellert P, Witham MD, Crombie IK et al. The role of perceived barriers and objectively measured physical activity in adults aged 65-100. *Age Ageing* 2015; 44: 384-90.
- Duncan F, Kutlubaev MA, Dennis MS et al. Fatigue after stroke: a systematic review of associations with impaired physical fitness. *Int J Stroke* 2012; 7: 157-62.
- Loureiro APC, Guarita-Souza LC, Lerdal A et al. A review of the relationship between poststroke fatigue and physical activity. *Topics in Geriatric Rehabilitation* 2014; 30: 296-306.
- Johnston M, Bonetti D, Joice S et al. Recovery from disability after stroke as a target for a behavioural intervention: results of a randomized controlled trial. *Disabil Rehabil* 2007; 29: 1117-27.
- Nicholson SL, Donaghy M, Johnston M et al. A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity. *Disabil Rehabil* 2014; 36: 1857-68.
- West T, Bernhardt J. Physical activity in hospitalised stroke patients. *Stroke Res Treat* 2011; 2012: 813765.
- Duncan F, Wu S, Mead GE. Frequency and natural history of fatigue after stroke: a systematic review of longitudinal studies. *J Psychosom Res* 2012; 73: 18-27.
- Duncan F, Kutlubaev MA, Dennis MS et al. Fatigue after stroke: a systematic review of associations with impaired physical fitness. *Int J Stroke* 2012; 7: 157-62.

5.4. Discussion

As hospital discharge is the proposed time for conducting the behaviour change intervention, further research is required to determine what happens in the first year post discharge to determine what will help stroke survivors maintain their high self-efficacy and intention to physical activity once discharged from hospital. Results from this quantitative study showed that fatigue may be a common barriers to physical activity at discharge from hospital with 45% of those interviewed believing being “too tired” was a major influence on their ability to increase their physical activity. Fatigue is a common complication after stroke and a systematic review of longitudinal studies has demonstrated that the frequency of fatigue can range from 35% to 92% and can be a persistent symptom after stroke at least for the first 36 months (Duncan et al., 2012). Another more recent review including 19 articles of 2072 stroke survivors and found that fatigue may be an important clinical determinant of a progressively disabling pattern of reduced physical activity and/or physical fitness, although the results were not conclusive (Loureiro et al., 2014). Further results from this quantitative study show that 31/50 (62%) of participants had no residual gait deficits, 11/50 (22%) had hemiparetic gait, 7/50 (14%) had shuffling gait and the remaining participant had both hemiparetic and shuffling gait.

A further limitation to this study could be the use of the Mutrie Scale, which only included 4 barriers and 9 motivators to physical activity and was not specifically designed for stroke survivors (Mutrie et al., 1993). However, members of the research team had used the scale previously and found it quick and easy to administer (Payne et al., 2001). This was deemed necessary as a lot was being asked of each participant and asking a larger, more complicated questionnaire was deemed

too much for participants. To my knowledge there are no questionnaires specifically designed for stroke survivors that incorporate all potential barriers and facilitators to physical activity after stroke. A questionnaire such as the Craig Hospital Inventory of Environmental Factors (CHIEF) could have been utilised, but as this only includes environmental factors and further questionnaire would have been required, increasing participant burden (Han et al., 2005).

5.5. Conclusions

Self-efficacy and intention to physical activity were high prior to discharge from hospital, yet several barriers and facilitators to physical activity were perceived by stroke survivors that may alter this self-efficacy and intention once home from hospital. These data have implications for the development of the behaviour change intervention. The belief that “physical activity is good for health” needs to be built upon in the behaviour change intervention and strategies put in place to help participants tackle “being too tired” or “poor health” they may be facing through targeted goal planning. It is essential to ensure that exercise beliefs and preferences are taken into account when advising stroke survivors to be more physically active. The behaviour change intervention design must maintain self-efficacy and intentions in the first year post discharge from hospital. Table four details the take home messages from the quantitative study.

Table 4: Quantitative study summary

Quantitative study summary
<ul style="list-style-type: none">• Self-efficacy and intention to physical activity are high on discharge from hospital.• The most common motivating factor was 'physical activity is good for health' [34 (68%)].• The most common barrier was 'feeling too tired' [24 (48%)].• The walking tests did not influence participant self-efficacy or intention.• Behaviour change interventions need to be able to maintain this high self-efficacy and intention, during the first year post discharge from hospital

CHAPTER 6 Accelerometer validation study

6.1. Introduction

A feedback device was envisaged to be paramount to the behaviour change intervention to maintain self-efficacy and motivation. The original plan had been to use the OMRON-HJ-113-E pedometer as this had been previously validated in stroke survivors (Carroll et al., 2012). However, an opportunity arose to collaborate with a team at Newcastle University who had developed an accelerometer that incorporated an immediate feedback screen (similar to that of a pedometer). This was seen as an exciting opportunity to be able to have a monitoring device designed specifically for the needs of the behaviour change intervention. The device would not only be highly accurate but able to provide immediate feedback to the wearer on step count. The following chapter documents the body of work carried out to validate this device with stroke survivors.

6.2. Abstract

BACKGROUND: Accelerometers are a highly accurate way to determine step counts in any population group; however generally they do not provide immediate visual feedback on step count. Through collaboration with The Culture Lab at Newcastle University the aim of this body of work was to develop an accelerometer, validated in stroke survivors, that provides immediate visual feedback on step count to the wearer.

METHODS: Stroke survivors were recruited at discharge from seven hospitals after first ever or recurrent stroke. Participants performed a six minute walk test wearing a

prototype accelerometer from the Culture Lab at Newcastle University. Participants were video recorded while completing a six minute walk test to determine the actual number of steps taken during the walk. Video recorded steps were compared to the readings from the accelerometer. Data from these walks were to be used to change the algorithms of the accelerometer to ensure its accuracy with stroke survivors.

RESULTS: Ten participants took part in the study and 6/10 (60%) were men. Mean time since stroke was 29 days (SD=27.9 days). Four participants were unable to complete the full six minute walk test. The 10 participants walked a mean distance of 245 meters (SD=129m) and their mean walking speed was 0.79ms^{-1} (SD= 0.34ms^{-1}). Unfortunately The Culture Lab were unable to develop the accelerometer in the necessary time frame and therefore there are no data on the development of the accelerometer.

CONCLUSION: The device was not developed within the required time frame by the Culture Lab at Newcastle University, and therefore it was not possible to progress further using this device as part of the behaviour change intervention. Instead, the OMRON-HJ-113-E pedometer was selected for use in the behaviour change intervention. This pedometer had previously been validated in stroke survivors, although its use would be limited to stroke survivors in whom the device could detect steps accurately.

6.3. Background

Walking is an important mode of physical activity, as it is cheap, easy to undertake and can be done in any locations. One of the easiest ways to measure walking is by using a pedometer to record step count. There are many different makes and designs of pedometers, which vary in their levels of agreement with actual step count (Schneider et al., 2003). This may be due to several factors including the mechanism the pedometer utilises to detect steps or the pedometer's sensitivity at detecting steps (Schneider et al., 2003).

A previous study investigated the feasibility and acceptability of pedometers in detecting steps of stroke survivors (Carroll et al., 2012). 50 participants were asked to apply three OMRON-HJ-113-E pedometers: one around the neck and one above each hip. The OMRON HJ-113-E pedometer was chosen due to its greater accuracy when compared with mechanical pedometers in sedentary older women (McMurdo et al., 2010). Patients performed a short walk lasting 20 seconds, then a six minute walk test (in accordance with the American Thoracic Society's protocol 2002).

Video recordings of the walks determined the gold standard step count. Results showed that the accuracy of the OMRON-HJ-113-E pedometer was greatly reduced at gait speeds below 0.5ms^{-1} (Carroll et al., 2012). However, not all pedometers failed to detect steps at walking speeds less than 0.5ms^{-1} . Slow gait speed, residual gait abnormalities and walking aids were highly inter-related. It was therefore difficult to determine which had the greatest impact on agreement of pedometer step count and the gold standard step count. Undercounting was common to almost all pedometers, even for higher walking speeds, however undercounting appeared to be systematic and therefore changes in step count would still be detected (Carroll et al.,

2012). These findings confirm those of two smaller studies in stroke survivors, which used mechanical and spring levered pedometers rather than piezoelectric pedometers (Macko et al., 2002, Elsworth et al., 2009).

A systematic review has found that accelerometers are both valid and reliable in measuring physical activity after stroke (Gebruers et al., 2010). Accelerometers measure body movements in terms of acceleration, which can be used to interpret physical activity over time. Through piezoelectric sensors accelerometers can objectively capture body movement and provide information on the total amount, intensity, duration and frequency of physical activities. However, accelerometers are more expensive than conventional pedometers and require data to be downloaded onto computers, so immediate feedback on step count is unavailable to the wearer (Warms, 2006). Immediate feedback is envisaged to be a key component of the behaviour change intervention, as feedback will promote independence and maintain motivation. Therefore, an accelerometer would not be a suitable feedback device for the behaviour change intervention. Consequently a collaboration was set up with the Culture Lab at Newcastle University. “The Culture Lab is the focal point for research in human-computer interaction, ubiquitous computing and digital creative practice at Newcastle University and its members engage in experimental and cross-disciplinary projects in interaction design and creative digital arts in a technologically rich and custom designed environment” (Newcastle Culture Lab, 2013). The Culture Lab agreed to develop an accelerometer that would accurately detect the step counts of the majority of stroke survivors, as well as provide immediate feedback on step counts to the wearer of the accelerometer.

Therefore, the aim of this study was to provide data to validate the Newcastle University accelerometer for use with stroke survivors.

6.4. Methods

6.4.1. Recruitment of participants

Ethical approval was obtained from the South East Scotland Research Ethics Committee 01 on 11th of January 2012. A copy of the ethical approval can be found in appendix 4. Patients admitted with an acute stroke (first-ever or recurrent) ready for discharge from six stroke units in Lothian (two acute, three rehabilitation and one mixed rehabilitation/acute unit) were identified in consultation with clinical teams between 28/02/2012 and 14/05/2012. Potential participants had to be able to walk independently, without human assistance, either with or without a walking aid; have completed their in-patient rehabilitation and be ready for hospital discharge; be able to give informed consent; carry out simple instructions to safely perform the walk and be medically stable. Previously reported criteria were used to determine if patients were medically stable to partake in the study (Mead et al., 2007b). Patients were medically unstable if they had: uncontrolled angina pectoris, resting systolic blood pressure >180mmHg or resting diastolic blood pressure >100 mmHg, resting heart rate >100 beats per minute, unstable or acute heart failure, uncontrolled systemic illness, uncontrolled visual or vestibular disturbance, recent injurious fall without medical examination and proven inability to adhere to the exercise programme (Mead et al., 2007b). A copy of the participant information sheet and consent form can be found in appendix 5.

6.4.2. The walk

Potential participants were asked to complete a six minute walk test (in accordance with the American Thoracic Society's Protocol 2002) with a prototype accelerometer, from the Culture Lab at Newcastle University, attached to the waist band above the hip that was not affected by their stroke. Placement above the unaffected hip was chosen as it was found to be a more accurate location at recording steps than above the affected hip when using the pedometers (Carroll et al., 2012). The Culture Lab also felt this would be the most accurate location for the accelerometer to detect steps accurately. Participants were asked to walk up and down a corridor on the ward (of pre-determined length) for six minutes. Due to the configuration of the wards and being unable to take patients away from the wards, the walks were not always conducted in a corridor 30m in length in accordance with the American Thoracic Society's Protocol. The walk was video recorded and the distance the participant walked noted using a measuring tape. Distance walked and the time taken to walk this distance (recorded by the video-recorder's timer) were used to calculate the participant's gait speed (ms^{-1}). The video recordings were replayed on a computer screen and one researcher (SN) was able to determine the actual step counts taken by each participant by counting their steps during the walk. For participants who stopped early and did not wish to continue walking; or participants who were deemed unsafe during the walk; the timer was stopped and the distance walked recorded as per the six minute walk test protocol (ATS, 2002).

6.4.3. Device development

The videos recordings, step counts determined from the video recordings and the data produced from the accelerometer for each of the 10 study participants' walks were sent to the team at Newcastle University for analysis. The data would be analysed by the team in Newcastle to ensure the accelerometer accurately detected the steps of stroke survivors' altered gait patterns. This would allow changes to the algorithm of the accelerometer to be made and the visual output screen to be fitted ready for use in the behaviour change intervention.

The following methodology was proposed by the Newcastle team to analyse the data that had been sent to them:

Walking is made up of three components including forward (roll), vertical (yaw) and side (pitch) movement (Zhao, 2010). An accelerometer will sense acceleration along each of these three axes. At least one axis has relatively large periodic acceleration changes, no matter where the accelerometer is worn, so peak detection and a dynamic threshold-decision algorithm for acceleration on all three axes are essential for detecting a unit cycle of walking (Zhao, 2010). Initially for the purposes of analysis the data would be smoothed, where by all three axes of data are combined, and a dynamic threshold calculated. A 50 sample window is viewed, where by the system will continuously update the maximum and minimum values of the three axes. The average value over these 50 samples is called the dynamic threshold level (Zhao, 2010). For the following 50 samples, this threshold is used to determine whether a step has been taken. The process is repeated every 50 samples and improves the accuracy of the accelerometer in counting steps (Zhao, 2010). The smoothed, filtered data has to cross the dynamic threshold at a negative gradient for a

step to be detected. Further analysis of the device was required to ensure the accelerometer was not too sensitive at detecting accelerations. This would be done by analysing the time window. The time window discards any small movements of the device, which are not actual steps. Normally it is assumed that people can walk as slowly as one step every two seconds; however this is reduced in stroke survivors who can walk as slowly as one step every four seconds. Therefore, the interval between two valid steps is defined as the time window [0.2s to 4.0s], steps out with this time window would be discounted (Zhao, 2010).

6.5. Results

6.5.1. Participant demographics

Ten participants took part in this observational trial, with 6/10 (60%) of the participants male and 9/10 (90 %) of strokes were ischaemic. The mean time since stroke was 29 days (SD=27.9 days), and 4/10 (40%) participants had been left with a residual gait abnormality, such as shuffling or hemiparesis, with 3/10 (30%) participants requiring a walking aid.

Four participants were unable to complete the six minute walk test, but the distance they walked and the time taken to walk this distance were recorded. All 10 participants walked a mean distance of 245 meters (SD=129m) and their mean walking speed was 0.79ms^{-1} (SD= 0.34ms^{-1}).

6.5.2. Results from The Culture lab at Newcastle University

The team in Newcastle proposed that the main problems with the stroke survivors gait were that they walked slowly and irregularly with little impulsion. Therefore, the

algorithm of the accelerometer would need to be changed accordingly to ensure accurate recording of step count. However, it is unclear whether this work was ever carried out or not as no device was ever produced by the team at Newcastle University. Our team at Edinburgh received two slides of data from Newcastle showing that the data sent to Newcastle had been analysed but no device or main body of results were delivered.

6.6. Conclusions

It was disappointing not to be able to use a device developed by the Culture Lab in Newcastle. It has been essential to use this collaboration as a positive learning experience and understand that in research things do not always go according to plan. To have an alternative plan is an essential part of learning and research. As a result of being unable to use the Newcastle accelerometer the OMRON-HJ-113E pedometer was selected to detect step counts in the behaviour change intervention. Although there were limitations to using this device, evidence suggested it would detect the step counts of stroke survivors who walked greater than 0.5ms^{-1} (Carroll et al., 2012). In addition, it was reassuring to see that the mean walking speed of the 10 participants was greater than 0.5ms^{-1} . This implied that the OMRON-HJ-113-E pedometer would detect the majority of stroke survivors' step counts who took part in the behaviour change intervention.

Now that all the preliminary work had been undertaken, the next stage of this PhD was to develop the behaviour change intervention using the data obtained from the

first four studies. The development of the intervention will be discussed in the following chapter.

CHAPTER 7 Design and development of the behaviour change intervention protocol

The following chapter discusses the development of the behaviour change intervention and how the preceding chapters (3-6) have played key roles in the development of this intervention.

To develop the behaviour change intervention it was essential to understand psychological theory and how this theory plays a key role in behaviour and behaviour change. Understanding psychological theory and applying this to the results from the systematic review, qualitative and quantitative studies allowed the determination of the most appropriate behaviour change techniques for inclusion in the behaviour change intervention.

7.1. Introduction

There is increasing recognition that interventions to change behaviour should draw on theories of behaviour and behaviour change in their development. The guidelines from the MRC on the development of complex interventions states “Developing, piloting, evaluating, reporting and implementing a complex intervention can be a lengthy process. All of the stages are important, and too strong a focus on the main evaluation, to the neglect of adequate development and piloting work, or proper consideration of the practical issues of implementation, will result in weaker interventions, that are harder to evaluate, less likely to be implemented and less likely to be worth implementing” (Craig et al., 2008). This quote demonstrates the importance of proper piloting and evaluation when designing and implementing a behaviour change intervention.

Best practice is to develop behaviour change interventions systematically. This should be performed using the best available evidence and appropriate theory, then to test the intervention using a phased approach, starting with a series of pilot studies targeted at each of the key uncertainties in the design and moving on to an exploratory and then a definitive evaluation (Craig et al., 2008).

Earlier chapters of this thesis detailed the preliminary work performed to establish the key components of the behaviour change intervention, producing the best available evidence in the field of physical activity after stroke. The systematic review, qualitative and quantitative studies provided valuable data on key barriers and facilitators to physical activity perceived by stroke survivors and also stroke survivors' self-efficacy and intention to physical activity. Figure five details the results from each of the preceding chapters and how these go on to inform the development of the key components of the behaviour change intervention.

Triangulation of the results from the preceding chapters is essential to fully interpret all the relevant data these studies have elicited. By researching the same topic (barriers and facilitators to physical activity after stroke) using three different research methods has allowed for a thorough examination of the phenomenon and validate why the intervention has been developed accordingly. How these three studies have influenced the key components of the behaviour change intervention are discussed in section 7.2.

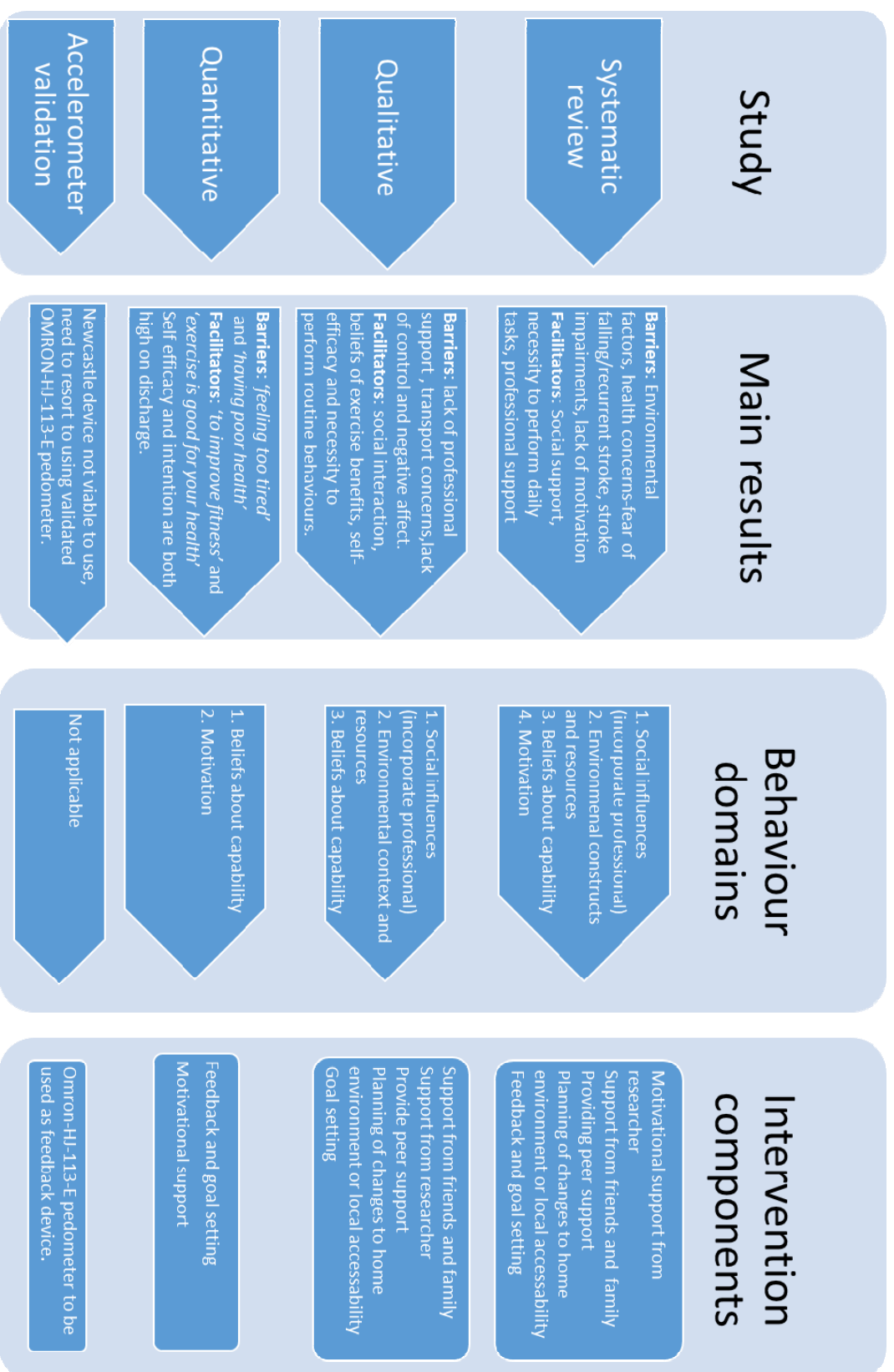


Figure 5: Results from preceding studies

7.2. Theoretical background to intervention domains

Theory provides a sound basis for designing interventions to change behaviour but offers little guidance on how to do this. As discussed earlier in section 1.10, there are three main reasons for advocating the use of theory in designing interventions.

1. Interventions are likely to be more effective if they target causal determinants of behaviour and behaviour change; this requires understanding these causal determinants, i.e. theoretical mechanisms of change.
2. Theory can be tested and developed by evaluations of interventions only if those interventions and evaluations are theoretically informed.
3. Theory-based interventions facilitate an understanding of what works and thus are a basis for developing better theory across different contexts, populations and behaviours (Michie et al., 2008).

From the three earlier studies (systematic review, quantitative and qualitative studies), the four theoretical domains that were most frequently reported and appeared to be the greatest influence on physical activity uptake after stroke included:

1. Beliefs about capabilities
2. Social influences
3. Environmental context and resources
4. Motivation

7.2.1. Beliefs about capabilities

The TDF construct of “beliefs about capabilities” was the most commonly reported domain within the qualitative interviews, and therefore would be pivotal in designing the behaviour change intervention. “Beliefs about capabilities” contains constructs such as self-efficacy, control, self-esteem, empowerment and optimism/pessimism and refer to a participant’s perceptions about their own abilities and control with respect to their physical activity. Many participants who took part in the qualitative interview study reported they lacked control over their physical activity. This lack of control was due to a number of reasons including their family’s fear of them falling and also a lack of services they were able to attend. The construct self-efficacy was also found to be highly important as found in the quantitative study, and was therefore believed to be an important construct to target as part of the behaviour change intervention.

7.2.2. Social influences

The systematic review highlighted that an important facilitator to increasing physical activity after stroke was the availability of social support. This social support included the possibility of meeting new people (Damush et al., 2007) (Patterson and Ross-Edwards, 2009) (Resnick et al., 2008) (Robison et al., 2009). Meeting new people was perceived to provide psychological and motivational support as it would give each stroke survivor an individual to talk to who had been through a similar situation. Similarly, providing professional support in guiding and facilitating physical activity was perceived as a facilitator in three studies from the systematic review (Patterson and Ross-Edwards, 2009) (Resnick et al., 2008) (Robison et al.,

2009). “Social influences” were also commonly reported in both the qualitative study. Within the qualitative study social interactions with friends and family were influential on the uptake of physical activity after stroke:

“it was in a group class and we had to do certain things(exercises) and they really encouraged you to do it. They didn’t bully you, and we all helped each other, which was very good. I thought it was very good.” 13:260

Therefore, “social influences” were considered to be an essential part of the behaviour change intervention, as social interactions with both professionals and peers were perceived to encourage and enable physical activity after stroke.

7.2.3. Environmental context and resources

The TDF construct of “environmental context and resources” was also a common theoretical domain that influenced physical activity uptake in both the systematic review and the qualitative study. Within the systematic review “environmental context and resources” was perceived as a barrier to physical activity after stroke and included physical difficulties accessing stroke services and the economic costs of a physical activity programme. The qualitative study also documented having areas to walk that were accessible from a person’s home, was also a facilitator to being more active after a stroke. Similarly a perceived barrier to being physically active was lack of support upon discharge from hospital, leading to a sense of abandonment due to not having services in place.

“I think it’s, I mean there’s such a lot of, even round here, I think there could be more things locally that could, you could get to or, you know...” 2:446

Therefore, “environmental context and resources” were deemed essential parts of the behaviour change intervention, as both the social and physical environment greatly influenced whether stroke survivors felt able to participate in physical activity.

7.2.4. Motivation

The TDF construct of “motivation” was the final construct believed to be imperative to the development of the behaviour change intervention. In the systematic review a lack of motivation was often cited as a barrier to the uptake of physical activity after stroke. However, a lack of motivation was not a predominant barrier in the qualitative study. This study showed some stroke survivors felt that they were motivated to be more physically active yet other reasons prevented them from being able to act on their motivation (e.g., their social circumstances or having access to resources). Similarly, data from the quantitative study alluded to high motivation amongst stroke survivors at discharge from hospital.

As discussed previously in section 1.12.1, feedback and goals setting were thought to be essential components of the intervention. These components were included in the intervention design as it was believed these would help to maintain motivation for those taking part in the intervention. This was especially important as it was already known self-efficacy and intention were high on hospital discharge and it was essential to maintain this.

7.3. Behaviour change techniques

Taking these four key theoretical domains it was then essential to determine which BCTs would be used to help tackle each domain. Previous research has determined which behaviour change techniques can best be used to target the theoretical domains (Michie et al., 2008). Figures 6-9 detail the four theoretical domains and the specific BCTs that are recommended to help alter each of these theoretical domains (Michie et al., 2008). The behaviour change techniques highlighted in green are those that were considered to be important to the development of the behaviour change intervention. Those emphasised in red are techniques that are detailed in more than one of these four theoretical domains.



Figure 6: Environmental context and resources domain and potential behaviour change techniques

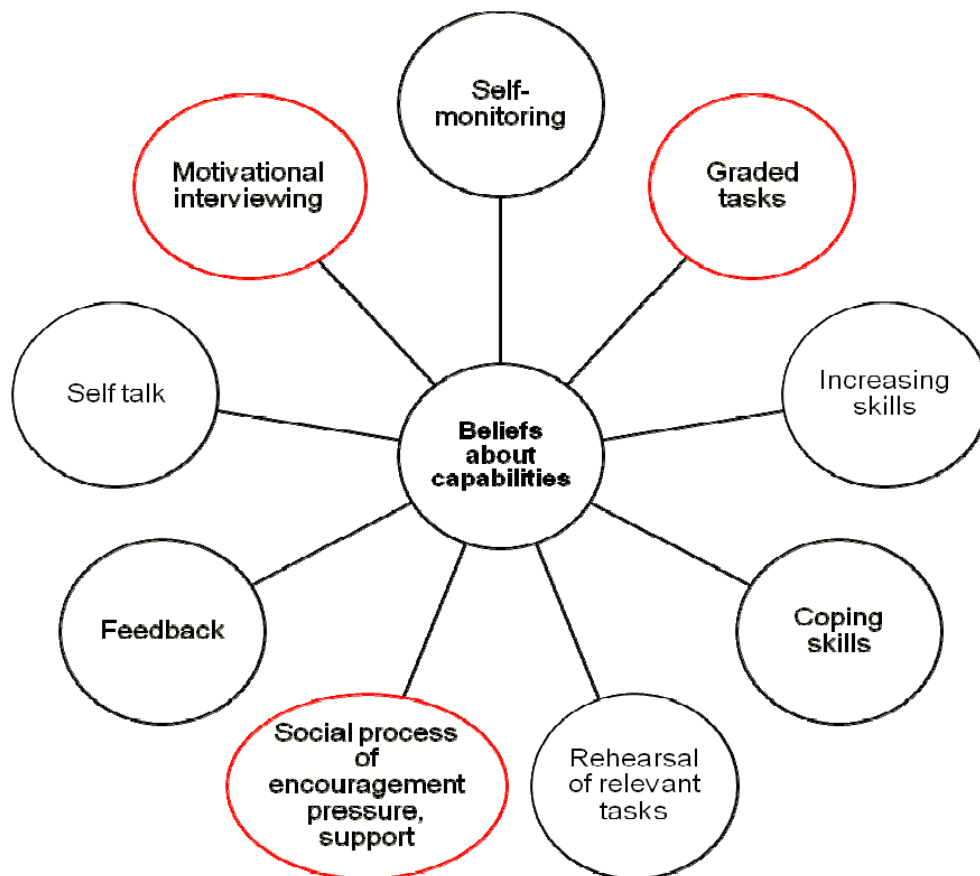


Figure 7: Beliefs about capabilities domain and potential behaviour change techniques

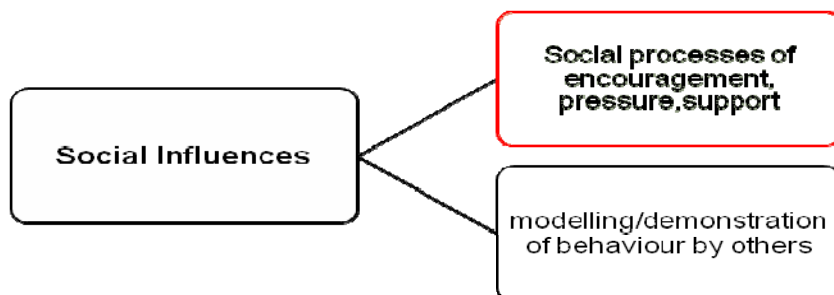


Figure 8: Social influences domain and potential behaviour change techniques

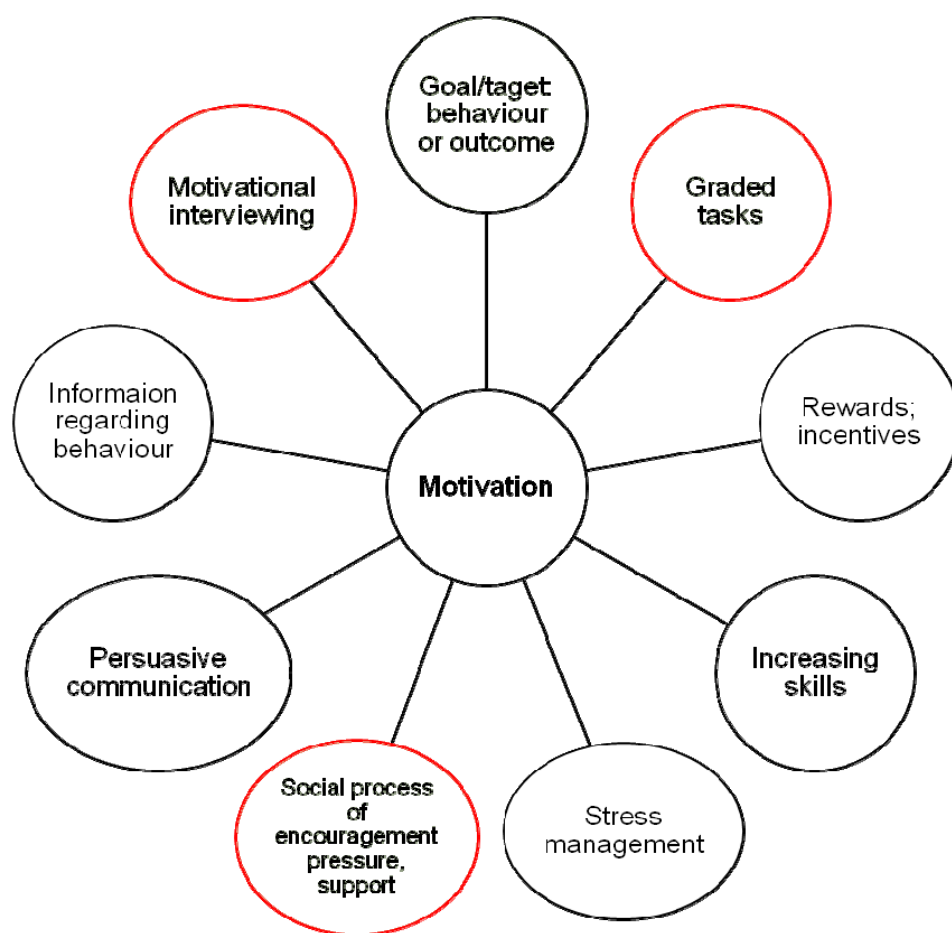


Figure 9: Motivation domain and potential behaviour change techniques

Figures 6-9 illustrate the numerous BCTs that could alter each of the theoretical domains. Therefore, careful consideration was required to determine which BCTs would be used as part of the behaviour change intervention.

Figure 6 details the theoretical domain of “environmental context and resources” and the BCTs that can be used to alter this domain. As “environmental changes” was the only BCT identified for this domain it would need to be incorporated into the behaviour change intervention. Environmental changes is defined as “change the environment in order to facilitate the target behaviour” (Michie et al., 2008). This would be done by asking participants to plan how they would go about doing physical activity in their local area. This would include thinking about the problems they could face in their own physical environment such as problems with access or public transport. Where available, guidance would be provided on stroke groups that may be available in the local area. It was envisaged that stroke groups would not only provide extra opportunity to increase physical activity, but provide social support for study participants.

Figure 8 shows the theoretical domain of “social influence” and the BCTs that can be used to alter social influences. The two behaviour change techniques identified by (Michie et al., 2008) were, “social processes of encouragement, pressure and support”; and “modelling/ demonstration of behaviour by others”. It was deemed most appropriate to use the BCT “social processes of encouragement, pressure and support” as this technique was also demonstrated to be useful in altering the other theoretical domains of “motivation” and “beliefs about capabilities”. Social processes of encouragement, pressure and support is defined as when others provide “social support (emotional): others listen, provide empathy and give generalised

positive feedback” (Michie et al., 2008). This BCT would be delivered to each stroke survivor both from a professional researcher and by involving friends and family throughout the intervention.

Figures 7 and 9 detail the BCTs suitable to help alter the domains of “motivation” and “beliefs about capabilities”. There were nine different BCTs that could influence each of these behaviour domains. To determine which BCTs would be incorporated into the intervention it was important to consider which techniques were influential in more than one of the behaviour domains. Therefore, the remaining techniques that would be included within the behaviour change intervention would be “graded tasks” and “motivational interviewing”. Graded tasks is defined as “easy tasks to perform, making them increasingly difficult until target behaviour performed”, while motivational interviewing is defined as “elicit self-motivating statements and evaluation of own behaviour to reduce resistance to change” (Michie et al., 2008). These BCTs would be incorporated by having regular meetings between the stroke survivors and researcher (SN) and incorporating graded tasks into each participant’s goal planning.

Work carried out prior to this PhD suggested that the intervention could be delivered to participants through a booklet with regular professional support and guidance on increasing and maintain physical activity (Johnston et al., 2007). The components of the intervention booklet were to be guided by the earlier studies. Therefore, other behaviour change techniques that identified as having the potential to influence the four main behaviour domains were also included in the design of the intervention. These techniques included feedback, coping skills, self-monitoring and goal setting. Each of these techniques will now be examined in more detail, including the

rationale for their inclusion and how they would be incorporated into the behaviour change intervention.

7.4. Rationale for each component of the intervention

To address all of the BCTs identified as having the potential to influence the four main theoretical domains, the intervention consisted of several key interacting components including:

1. A feedback device to provide daily step count
 - This would incorporate the BCTs of feedback, self-monitoring, graded tasks and goal setting.
2. A participant booklet
 - This would incorporate the BCTs of goal setting, self-monitoring, coping skills, graded tasks, environmental context and resources.
3. Motivational contact from the researcher
 - This would incorporate the BCTs of motivational interviewing, goal setting and social processes of encouragement, pressure and support.
4. A group session with other stroke survivors
 - This would include the BCTs of social processes of encouragement, pressure and support, environmental context and resources and feedback.

7.4.1. Feedback device

As previously discussed in section 1.12.1, knowledge is a key component of behaviour change, but on its own, it is not sufficient to bring about behaviour change.

It is believed knowledge promotes awareness of personal risk behaviour implying that people will only consider changing their behaviour when they become aware that they are potentially putting their health at risk (i.e. suffering a life changing event such as a stroke). Feedback has been shown to increase both awareness of health behaviour and intentions to change that behaviour (Brug et al., 1999) (Proper et al., 2003) (Watkinson et al., 2010). Feedback and self-monitoring have also been shown to be one of the key proven components of behaviour change interventions as highlighted in the NICE guidelines (NICE, 2014).

As part of the behaviour change intervention feedback on daily step count would be provided to each study participant. Before the intervention could begin, there was a choice of three potential feedback devices: a pedometer, a standard accelerometer or the Newcastle University accelerometer (chapter six). As the collaboration with the Culture Lab at Newcastle University had not produced a suitable device for the behaviour change intervention, this was no longer a viable option. A standard accelerometer (such as the ActivPAL™) could have been used to provide the feedback on step count to study participants. However, to provide feedback on daily step count, data would have to be downloaded onto computers and information relayed back to the participant. Realistically this would need to be done on a weekly rather than a daily basis. Providing weekly feedback on step count would be very time consuming as each participant would require two weekly visits to pick up and drop off the accelerometer for the data to be downloaded and then relayed back to the participant. This would also compromise the BCT of self-monitoring as participants would not be able to monitor their step goals on a daily basis. Therefore, participants

would be unable to determine if they needed to try and alter their steps to meet their daily or weekly step goals.

Another potential way to provide feedback on physical activity was through the use of pedometers. Pedometers are a simple and effective way of providing feedback when trying to increase physical activity through walking. Pedometers are very simple to wear, cheap and can provide quick daily feedback on step count, without the need to download data onto a computer (Macko et al., 2002). This would allow for easy, immediate feedback which was paramount to the intervention and allow daily self-monitoring of the participants step goals. Therefore, pedometers were judged to be the most suitable feedback device for providing feedback on step count during the behaviour change intervention.

The OMRON-HJ-113-E pedometer would be used to provide the steps counts for the behaviour change intervention. This pedometer had been used previously as part of a feasibility study with stroke survivors (Carroll et al., 2012). This feasibility study found that the OMRON-HJ-113-E pedometer was feasible and acceptable to stroke survivors. However, generally the pedometer did not detect steps at gait speeds below 0.5ms^{-1} and tended to undercount steps above 0.5ms^{-1} (Carroll et al., 2012). To successfully use this pedometer as part of the behaviour change intervention, stroke survivors who walked slower than 0.5ms^{-1} would be excluded. For the majority of stroke survivors who walked faster than 0.5ms^{-1} , the majority of steps would be recorded by the pedometer. Although the pedometer did undercount steps at speeds greater than 0.5ms^{-1} it was not considered to be a crucial issue for the study. This was due to the systematic nature of the undercounting, and although steps recorded may be lower than the actual steps taken, participants would still be able to see their

weekly progress in increasing their step count (Carroll et al., 2012). Although potentially less accurate than an accelerometer, the issues surrounding the practicalities of using an accelerometer and the need to download data meant that the OMRON-HJ-113-E pedometer was judged the most suitable feedback device for the study, accepting that it may undercount but still provide evidence of changes in daily and weekly step count (Carroll et al., 2012).

7.4.2. Participant booklet

Alongside the pedometer the participant booklet would be another component of the behaviour change intervention. The aim of the participant booklet would be to target the key perceived barriers and facilitators to physical activity after stroke as highlighted in chapters 3-5. A participant booklet was considered an appropriate method to relay information to participants, as similar strategies have already been successfully implemented with stroke survivors. “The Stroke Workbook” intervention was designed to enable patients and carers to take control of their recovery by encouraging positive self-management during recovery from stroke (Johnston et al., 2007). Using behaviour change techniques and with the support of a trained facilitator, this intervention guided stroke survivors and families to:

- Draw on their personal coping skills
- Focus on what they can do and not on what they cannot
- Take an active role in recovery
- Set personal and realistic active goals

- Engage in their recovery by working in partnership with the multidisciplinary stroke team
- Seek out new information

“The Stroke Workbook” intervention was tested in a randomised controlled trial with 203 stroke survivors (Johnston et al., 2007). Those who received the workbook and had support from a trained facilitator, showed reduced disability by six months post stroke when compared with those who did not receive the intervention workbook. In addition, those who received the workbook had high self-efficacy regarding their recovery, meaning they were confident in their recovery (Johnston et al., 2007).

“The Stroke Workbook” is referred to in the SIGN 118 Stroke Rehabilitation Guidelines 2010 and recommended in 'The Better Heart Disease and Stroke Care Action Plan' (NHSScotland, 2009).

The booklet for the planned behaviour change intervention consisted of four sections (i) increasing motivation, (ii) social support, (iii) action and coping planning (iv) step diaries to record daily step counts.

- (i) *Increasing motivation:* Although a lack of motivation was not evident from the qualitative interviews, this was reported in the systematic review. As previously documented, benefits of behaviour change interventions are often lost after the intervention has ended (McMurdo et al., 2010). To try and prevent this, a section was included within the booklet to help to increase and maintain motivation to physical activity. From the quantitative data analysis it was clear that self-efficacy and

intention to be physically active are high at hospital discharge. Provision of a motivation section within the booklet would allow the maintenance of self-efficacy and intention once the participant had returned home from hospital.

- (ii) *Social support*: Social support was a perceived facilitator to physical activity in both the systematic review and qualitative interview studies. Social support was seen as a facilitator to maintaining motivation to increase physical activity, similarly the opportunity of meeting new people (i.e. at an exercise class) was viewed a facilitator to increasing physical activity. To include these important facilitators within the behaviour change intervention participants' friends and family were invited to engage with the intervention to provide long term support, encouragement and guidance.
- (iii) *Action and coping planning*: Action planning (or goal setting) and coping planning are considered important components in behaviour change (Sugavanam et al., 2013). Action planning is the post-intentional process that links goal-directed responses to situational cues by specifying when, where, and how to act in accordance with one's goal intention (Gollwitzer and Oettingen, 1998). People who form action plans are more likely to act in their intended way and initiate their goal behaviour quicker (Gollwitzer and Oettingen, 1998). Coping planning is an independent planning cognition that prepares a person for successfully coping with situations where by their action plans do not follow through (Sniehotta et al., 2005). Anticipating such situations allows for proactive preparation of

strategies that aim to prioritise the intended behaviour. This can help a person to overcome an obstacle and cope with difficulties that arise (Sniehotta et al., 2005). It was evident from the systematic review, qualitative and quantitative studies that there may be an array of barriers that inhibit physical activity post stroke. As was evident from the quantitative study, fatigue can prove to be a major barrier to physical activity after stroke with 48% participants reporting they were “too tired” to exercise. Similarly in the qualitative study 5/13 (38%) participants reported fatigue as having a negative effect on their ability to be more physically active. If a study participant was able to develop an action and coping plan to deal with fatigue this may allow the participant to increase their physical activity whilst remaining aware that there may be days when they feel tired and need to rest.

- (iv) *Step diary*: The step diary was included in the participant booklet to enable participants to monitor their own improvements in physical activity throughout the behaviour change intervention. Being in control of their steps and having this daily feedback of their achievements would empower the participants and enhance their feelings of self-efficacy and control (Johnston et al., 2007).

A copy of the behaviour change intervention participant booklet can be found in appendix 6.

7.4.3. Professional motivational contact

The qualitative interview study highlighted that many participants reported insufficient support from healthcare professionals after stroke. The behaviour change technique “social processes of encouragement, pressure and support” was also highlighted as influential in three of the four main behaviour domains highlighted earlier. Therefore, it was deemed necessary to ensure regular professional contact with participants to provide support, guidance and encouragement throughout the intervention. This support would take the form of a weekly telephone call and at least three visits to the participant’s home. Each weekly telephone call would be conducted with the primary aim of collecting daily steps and setting the following weeks’ target with the participant. However, this would be an ideal time, each week to check in with each participant to make sure they are still motivated to continue with the study. Any areas of concern, or problems that are being encountered could be discussed with the researcher and resolved for the following week.

7.4.4. Group session

The systematic review and qualitative interview study identified social support as key to engaging in physical activity post stroke. Support from family, friends and professionals would be encouraged as part of the booklet, but peer support could also be an essential aspect of social support. A group session between study participants would also be incorporated into the behaviour change intervention. The aim of the group session would be to provide peer support for each study participant, encourage group participation in physical activity and increase the opportunity for social support.

A “lack of knowledge” about services and support in the local community was a perceived barrier to physical activity documented in the qualitative study. At the group session participants would be able to discuss with other study participants the services they have been able to access within the community that may be of benefit to other participants. “Beliefs about capabilities” was reported as a barrier to participation in physical activity from the interview study. A group session, half way through the intervention, would allow each participant to meet other stroke survivors experiencing similar situations as themselves. Participants could provide peer support and encouragement to each other that they may not be able to get from friends and family. This peer support could be paramount in maintaining motivation and more importantly self-efficacy throughout the study, and during the first year after stroke.

7.5. Proposed experimental design and methodology

Figure 10 details the design and methodology of the proposed intervention. Each of the components of the intervention are described in detail throughout sections 7.5 and 7.6.

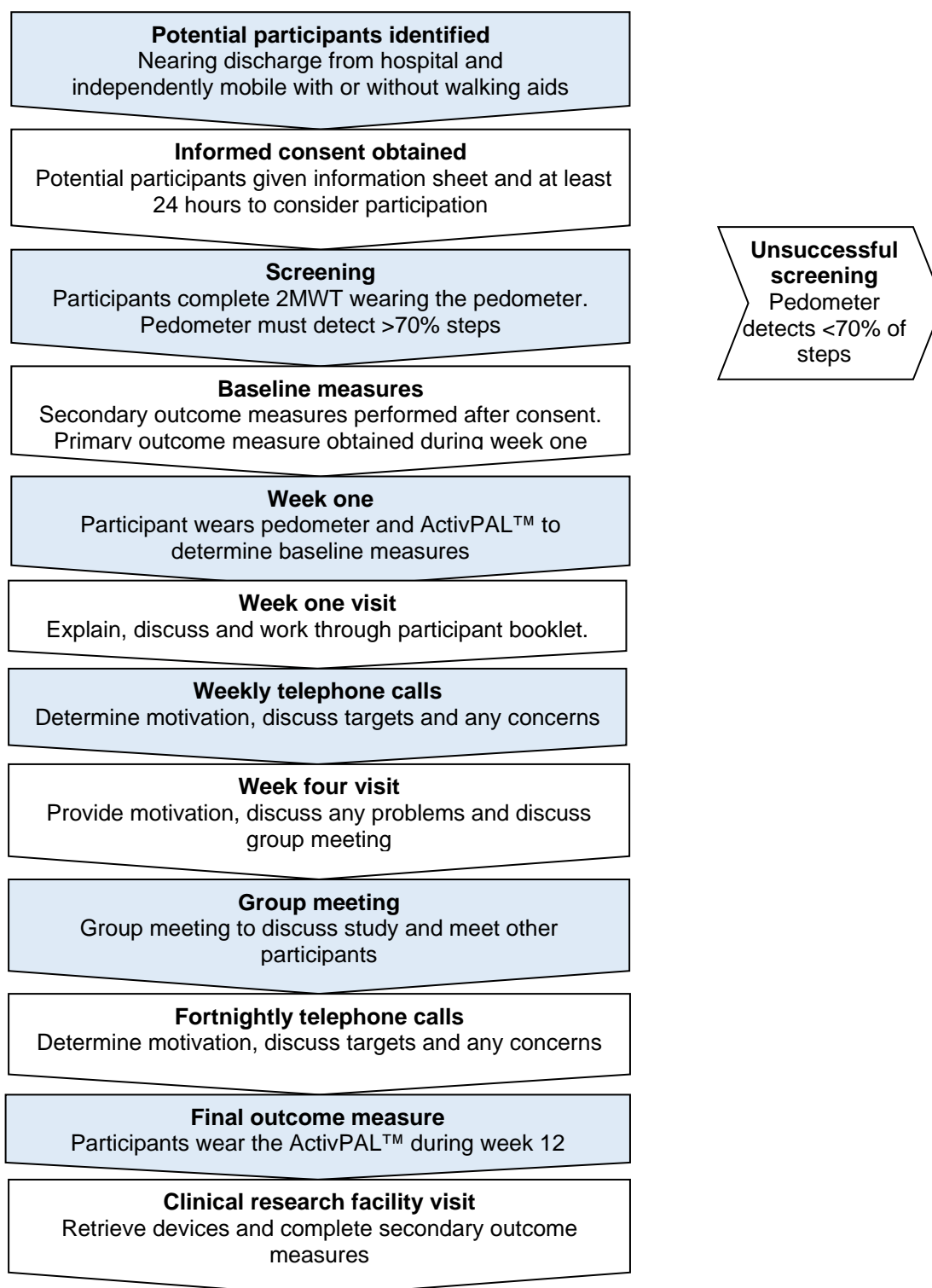


Figure 10: Flow diagram of behaviour change intervention protocol

7.5.1. Recruitment

Participants would be recruited from six recruitment sites throughout Edinburgh and the Lothians. These included the acute stroke unit and combined assessment unit at The Royal Infirmary of Edinburgh, the acute stroke units at the Western General Hospital and St Johns Hospital and three stroke rehabilitation units at Liberton, Astley Ainslie and Royal Victoria Hospitals respectively. Stroke survivors completing their in-patient treatment and rehabilitation would be approached shortly before discharge. Potentially suitable participants would be identified by the ward physiotherapist, medical team, nursing staff and the researcher. If a potential participant has mild dysphasia, the Speech and Language Therapists would be engaged to determine the best way to communicate with the potential participant and obtain consent. The intervention will then be discussed with the potential participant, an information sheet given to them and at least 24 hours allowed to consider participation in the behaviour change intervention.

7.5.2. Inclusion criteria

Participants must be able to walk independently, without human assistance, either with or without a walking aid. Participants must have completed their in-patient rehabilitation and be ready for hospital discharge, returning home from hospital rather than into residential care. Participants must be able to give informed consent and carry out simple instructions to safely perform the intervention in their own home with the help of the researcher (SN).

7.5.3. Exclusion criteria

Potential participants would be excluded if they have any of the following previously determined criteria: severe dysphasia, confusion, visual impairments severe enough to prevent informed consent or impair safety in exercise or medical contraindications to exercise training (i.e. uncontrolled angina pectoris, resting systolic blood pressure >180mmHg or resting diastolic blood pressure >100 mmHg, resting heart rate >100 beats per minute, unstable or acute heart failure, uncontrolled systemic illness, uncontrolled visual or vestibular disturbance, recent injurious fall without medical examination and proven inability to adhere to the exercise programme) (Mead et al., 2007b).

7.5.4. Screening

The potential participants would have to pass a screening test to be fully eligible to take part in the study. The screening was introduced to prevent those potential participants in whom the pedometer does not accurately detect steps (likely due to them walking slower than 0.5 ms^{-1}) from taking part in the study. Potential participants would be asked to complete a two minute walk test with the OMRON-HJ-113-E pedometer attached to their trouser waist band above their unaffected hip. This location was chosen as it was previously was found to be the most accurate in detecting steps of stroke survivors (Carroll et al., 2012). The pedometers must detect at least 70% of the participant's steps for them to be eligible to take part in the study. This cut-off was chosen as analysis from the previous study had shown that below 70% accuracy could be very variable, potentially due to participant gait speed (Carroll et al., 2012). To determine actual (gold standard) step count for each

potential participant, steps would be counted (by the researcher SN) during the two minute walk test using a hand tally counter. Once the walk was completed the pedometer and hand tally counter readings would be compared. This would be done to determine if the pedometer had detected the required 70% of steps. If the screening was successful, the potential participant would be fully eligible for the study. If the pedometer did not detect 70% of steps the potential participant would not be eligible to continue in the behaviour change intervention. All participants who pass the screening would complete The Montreal Cognitive Assessment (MOCA) (Nasreddine et al., 2005). This would allow the research team to identify cognitive problems that may influence the participant's ability to comply with the intervention. The MOCA would not be used to determine the capacity of the individual to take part in the behaviour change intervention. However, the MOCA would give baseline information that would allow the study team to explore whether participants who were not able to comply with the intervention were more cognitively impaired compared with those who successfully complied with the intervention.

7.5.5. Feasibility and acceptability outcomes

The intervention will initially be trialled as a feasibility and acceptability study. Therefore, there will be no control group as part of the study and the trial of the intervention will not be powered to determine if the intervention does significantly increase physical activity after stroke. Exploration of the feasibility and acceptability of the behaviour change intervention will be assessed by recording the following seven outcomes:

1. How many eligible patients approached?
2. How many agreed to participate?
3. The number of participants who drop out of the study and the reasons for dropping out
4. The numbers of missing step counts in the step diaries due either to pedometer failure or participants forgetting to record steps
5. The duration of each telephone call and meeting with each participant
6. The interest and attendance at group meeting
7. The responses from the participant feedback form

Feasibility and acceptability of the behaviour change intervention will be tested by detailing how many stroke survivors were eligible for participation from all stroke discharges at Edinburgh Royal Infirmary. The numbers of stroke survivors eligible for the study will be noted including how many agree to take part and how many agree to participate but subsequently dropout. The length of time for each phone call and visit to each participant will be recorded. This will determine the input required from the researcher to undertake the weekly phone calls of the study. Any missing data from the participant's step diary and the reasons for these missing data will be recorded, to help determine how acceptable the diaries are to participants.

Acceptability of the behaviour change intervention will be assessed by recording the dropout rate of the pilot study. Acceptability of the intervention will be determined by collating the number of patients who were approached by the study team and the number of eligible patients who were approached by the researcher but declined to

participate. The acceptability of the intervention will also be determined by collating data from the participant feedback form.

7.5.6. Outcome measures

In the first instance the aim of the pilot study would be to determine the feasibility and acceptability of the behaviour change intervention. This would include determining the feasibility and acceptability of the proposed outcome measures to be included in the behaviour change intervention. When progressing on to a main definitive trial of the intervention (after feasibility and acceptability had been ascertained) the primary and secondary outcome measures that would be used would include:

PRIMARY OUTCOME MEASURE: Although the OMRON-HJ-113-E pedometer would be used to provide daily feedback on step count to each participant, the primary outcome measure of the main intervention would be physical activity, specifically step count, measured using an activPAL™ accelerometer. Using an activPAL™ accelerometer would give a more detailed look at the individuals days i.e. time spent sitting, stepping and standing and how these activities were broken up throughout the day.

The activPAL™ is an accelerometer, worn on the anterior aspect of the thigh, which can record data continuously for up to seven days. The activPAL™ is a small and light-weight device that attaches securely to the skin, avoiding any swaying of the device independent of body movement. The device contains a sensing element, a microprocessor and a recording element. The sensing element of the activPAL™ is a uni-axial accelerometer which responds to gravitational acceleration as well as the acceleration resulting from segmental movement (PALtechnologies, 2010). The

microprocessor controls the processing and recording of the sensor signal and the communication with a host computer. Data are recorded at 10 Hz for each 15 second time interval (PALtechnologies, 2010). The activPAL™ interfaces via a docking station and USB connection with a Windows compatible computer. Using proprietary algorithms, the activity pattern can be analysed. The software allows data to be presented in various ways (weekly view or day view, graphically or quantitatively), according to the needs of the user (PALtechnologies, 2010). The activPAL™ classifies activity in terms of the time spent sitting or lying, standing, stepping, number of steps taken, cadence and the amount of sit-to-stand and stand-to-sit transitions. The activPAL™ has been validated in both in children and adults at differing walking speeds (Ryan et al., 2006) (Godfrey et al., 2007) (Harrington et al., 2011) (Oliver et al., 2011) (Davies et al., 2012). The activPAL™ has also recently been validated with stroke survivors as part of doctorate work, and it was highlighted that it may undercount steps (Sugavanam, 2014). However, this undercounting was systematic, so for the purposes of this research would be considered appropriate.

Physical activity data, recorded by the activPAL™, would be recorded during the participant's first week home after discharge from hospital and the final week of the intervention.

SECONDARY OUTCOME MEASURES: Secondary outcome measures would be performed initially when consent is obtained from the participant and at the end of the intervention. The secondary outcome measures will give a better understanding of each individual participants overall health and physical ability.

All these secondary outcome measures are included in the study to determine the feasibility and acceptability of their inclusion in a larger definitive trial, the details of each the measure are given below:

7.5.6.1. Short Physical Performance Battery (SPPB)

The primary outcome measure for the behaviour change intervention would be physical activity. Walking ability is considered one of the main components that influence physical activity (Brazzelli et al., 2011). Hence, the need to measure gait performance and lower extremity function was recognised. Data suggests that as much as 83% of stroke survivors present a postural imbalance (Tyson et al., 2006). This postural imbalance is linked to an increase in falls amongst stroke survivors. Therefore, balance was considered to be another important measure that would have an impact on physical activity. The SPPB is a group of measures that combines the results of the speed, chair stand and balance tests (Guralnik et al., 2000, Guralnik et al., 1994). The SPPB has been in previous studies as an outcome measure in stroke survivors (Macko et al., 2008) (Stuart et al., 2009). The SPPB has also been used as a predictive tool for possible disability and can aid in the monitoring of function in older adults. The scores range from 0 (worst performance) to 12 (best performance). The SPPB has been shown to have predictive validity showing a gradient of risk for mortality, nursing home admission, and disability. The SPPB has been shown to have high test-retest reliability 0.87 (CI:0.77-0.96) (Gómez et al., 2013). The SPPB was related to self-rated health, limitations in walking and climbing steps and to indicators of disability, as well as to cognitive function and depression. There was a

graded decrease in the mean SPPB score with increasing disability and poor health (Gómez et al., 2013).

7.5.6.2. The Nottingham extended activities of daily living (NEADL)

The impact of stroke on day-to-day life and overall health status were expected to be reflected in the physical activity goals set by the participants. They might also affect their performance in achieving their walking goals. Therefore, it was considered important to have a measure to capture quality of life, and the activities participants were undertaking on a daily basis. The NEADL is a measure of activities of daily living specifically designed for stroke survivors (Nouri and Lincoln, 1987). This measure would allow measurement of improvements in participant's daily abilities by recording what they are able to do independently or whether they require help to perform daily activities (Nouri and Lincoln, 1987). The NEADL was found to be a reliable and symmetrical, concurrently valid with no floor and ceiling effects (Sarker et al., 2012). However, the test-retest mean differences and reliability coefficients for the NEADL were found to be 0.6 \pm 5.6 (Green and Young, 2001).

7.5.6.3. Euro-QOL 5Q (EQ-5D-5L)

The EQ-5D-5L is a standardised measure of health outcomes looking at the quality of life of the respondent. The EQ-5D-5L has been shown to be a valid, concise and simple measure in measuring general health status after stroke (Hunger et al., 2012, Golicki et al., 2015a). It has also been shown stroke survivors that the EQ-5D-5L was consistently responsive, showing moderate ES (0.51-0.71) and moderate to large SRM (0.69-0.86) (Golicki et al., 2015b). Inclusion of this measure in a definitive trial

would show if increasing physical activity during the behaviour change intervention had any influence on the general health of the study participants.

7.5.6.4. Hospital anxiety and depression scale (HADS)

The HADS is a validated scale used to detect the presence of anxiety and/or depression in a population (Zigmond and Snaith, 1983). Anxiety and depression are both common after stroke and the HADS has been shown to accurately detect both anxiety and depression in stroke survivors (Sagen et al., 2009) (Campbell Burton et al., 2013) (Hackett and Pickles, 2014). Anxiety and/or depression may influence physical activity after stroke and may influence a stroke survivor's ability to undertake the behaviour change intervention.

7.5.6.5. Fatigue assessment scale (FAS)

Fatigue is a common problem after stroke, which may influence the uptake of physical activity (Duncan et al., 2012). The FAS contains 10 statements where the respondent describes how they usually feel. The responses to the statement are graded from 1="never" to 5="always". The FAS has been found to be valid and feasible for use with stroke survivors (Mead et al., 2007a). The FAS (out of five fatigue scales determined by a panel of experts to have best face validity) had the narrowest limits of agreement for total score indicating that it had best test-retest reliability (Mead et al., 2007a).

7.6. Intervention plan

7.6.1. Baseline data

At discharge from hospital, participants would receive the OMRON-HJ-113E pedometer and the activPAL™ accelerometer. During their first week home, participants would wear both of the devices daily and record their daily steps (from the pedometer) in their step diary. The total weekly step count from the first week would be used as the participant's "baseline" step count. Subsequently, from week two, participants would be set a 5% increase in their weekly step target. A 5% target was set because previous work with sedentary older women had successfully used walking targets of 20% over a month (McMurdo et al., 2010). If the weekly step target could not be achieved the step target would remain the same for the following week. The activPAL™ accelerometer would provide baseline physical activity data which will be downloaded off-site and used as primary baseline physical activity data.

7.6.2. Week one visit

At the end of week one the researcher would visit each participant in their own home. At this meeting the researcher would work through the behaviour change intervention booklet with the participant and discuss

- the benefits and possible risks of increasing walking after stroke
- how family and friends will feel about the participant trying to increase their walking
- the participant's intention and self-efficacy towards increasing their walking

- action and coping plans for each participant and the goals they wish to achieve
- how participants follow their step targets and step diaries each week.
- willingness to attend a group session with other stroke survivors

To encourage social support, family and/or friends would be invited to attend this session, provided the participant is happy for them to do so. Including family and/or friends in this meeting may make them more likely to engage in the behaviour change booklet with the participant. Support from family and friends is likely to be essential in providing participants with guidance and encouragement throughout the intervention. Continued social support would help the participant maintain motivation during the intervention and once the intervention has ended.

7.6.3. Participant booklet

The rationale for the four sections of the participant booklet has been discussed earlier in this chapter (section 7.4.2). The following subsections describe the contents of each of the four sections. A copy of the participant booklet can be found in appendix 6.

7.6.3.1. *Increasing motivation*

The first section will focus on the possible benefits and risks of increasing walking activity, i.e. increasing walking may

- boost energy

- lower blood pressure and cholesterol, which may protect against recurrent stroke
- control body weight
- prevent walking becoming difficult
- increase fitness
- strengthen bones

However, by increasing walking, participants may find that they

- become tired, especially if doing too much too quickly
- develop muscle pain and aching

Participants will be informed that they may experience some muscle aching and fatigue while trying to increase their physical activity, but that this is likely to wear off after a few days.

The risk of a cardiac event as a result of increasing walking is negligible. In people attending cardiac rehabilitation programmes, the risk of cardiac arrest is at a rate of 1 in 12 000 to 15 000. It is highly unlikely that the stroke survivors participating in this behaviour change intervention would reach this intensity of aerobic exercise through walking alone. Therefore, the risk of a cardiac event in this behaviour change intervention is very low. However, those participants for whom exercise is contraindicated would be excluded from participation (see previous exclusion criteria 7.5.3).

Participants would be advised that if they begin to feel unwell during walking, they must stop immediately and seek medical advice. Participants would be reassured that the overall risk of a heart attack from walking is low.

7.6.3.2. Social support

At the week one visit the presence or absence of social support networks (friends and family) would be established. The researcher would discuss with each participant how their family and friends would feel about them increasing their walking.

Participants would be encouraged to, and be given guidance on, attending stroke groups or walking groups to obtain peer support.

The researcher would discuss with the participant whether he/she would be willing to meet other participants of the intervention as part of the group meeting. This would be re-visited with the participant at the week four visit.

The participant's family or friends would be invited to attend the week one visit at the discretion of the participant. Family members and/or friends would be given an information sheet about the intervention and also information on how to support the participant to increase their walking throughout the intervention.

7.6.3.3. Action and coping planning

Participants would document their intention and self-efficacy towards increasing their walking in the form of action and coping plans. Participants would be encouraged to think about how to incorporate more walking into their daily lives e.g. walk instead of taking the car, use stairs instead of lifts, breaking periods of prolonged sitting with walking.

At the baseline meeting the researcher would help each participant set specific walking goals that they wish to achieve for the duration of the intervention. These goals may be to walk a specified distance or walk for a specific length of time to complete a task such as managing to go and do the shopping unaided. Action plans would be written by the participant to enable them to achieve their desired goals. The action plans would break the individual's goals into smaller achievable targets, helping the participant achieve the goals that they have set. Coping plans would then be devised with each participant in accordance with their goals. Coping plans are designed to help the participant deal with any difficulties they may encounter whilst trying to follow their action plans. Participants plan for these potential difficulties by making the coping plans. Coping plans will detail how they think they will overcome the difficulties they might encounter. Once coping plans are in place it would be hoped that participants would be less likely to quit their desired goals, as they would have already thought about and planned their responses to potential difficulties.

The practicalities of attending exercise classes and walking more frequently would be discussed with each participant. Physical environmental factors, such as difficulty with transport and access to services, would also be discussed with each participant. Transport services and lift share or volunteer driver services may help participants become more independent and physically active out with their own home; these would also be discussed.

7.6.3.4. Step diary

Participants would wear the pedometer for the entire duration of the behaviour change intervention. Weekly step targets would be set based on their "baseline" step

count obtained during the week one. Participants would be asked to keep a daily diary of their step counts to provide motivation through feedback and to allow monitoring of daily progress. Each day, participants would detail any reasons why they were unable to achieve their step target such as “not feeling well” or “poor weather”.

7.6.3.5. Feedback form

The participant booklet will include a feedback form. As this would be a feasibility study, it would be important to ascertain what the participants felt about each aspect of the behaviour change intervention. Participants would be asked to complete the feedback form at the end of the 12 week behaviour change intervention. The feedback form would be included within the workbook to help determine the feasibility and acceptability of the behaviour change intervention. The participant feedback form contains six questions and participants would be asked to circle the answer they felt was most appropriate to their experience of the study. The questions in the feedback form will be:

1. **Do you think the study was:** Too long? Too short? Just the right length?
2. **How easy did you find reading the step counter?** Very easy; Quite easy; Neither easy nor difficult; Quite difficult; Very Difficult.
3. **How easy did you find putting on the step counter?** Very easy; Quite easy; Neither easy nor difficult; Quite difficult; Very difficult.
4. **How easy was the booklet to follow?** Very easy; Quite easy; Neither easy nor difficult; Quite difficult; Very difficult.

5. **Were the telephone calls from the researcher:** Too frequent? Not frequent enough? About right?

6. **Were you satisfied with the help and advice the intervention gave you?**

1 2 3 4 5 6 7 8 9 10

(totally unsatisfied)

(totally satisfied)

7.6.4. Motivational telephone calls

As discussed in section 7.4.3 the primary objective of the telephone calls would be to regular, professional support during the intervention and to set weekly step targets.

During these telephone calls the participant would be provided with feedback, general encouragement/motivation and have the ability to ask the researcher (SN) any questions or concerns that they may have. To help conduct the telephone calls and understand more about Health Psychology, SN attended Health Psychology meetings at the Universities of Aberdeen and Newcastle twice a month. Although the concept of motivational interviewing was discussed at these meetings, no formal training was given.

At these telephone calls the participant would also discuss their weekly step targets. If the participant had achieved the previous week's step target, the following week's step target would be set at 5% higher. If the previous week's target had not been achieved, the reasons for this would be discussed with the participant and the following week's target would remain the same.

After every telephone call the main points of discussion with the participant would be documented, including any issues raised how these were addressed and whether the participant had been successful in achieving their step target. The duration of the

telephone call would also be recorded to help determine the feasibility and ease of delivery of the intervention.

7.6.5. Week four visit and group meeting

The participants would receive a second visit from the researcher (SN) at the end of week four. This visit is primarily to boost motivation, discover how the participant has found the first month of the intervention and continue to provide support and encouragement. The researcher would again discuss the group meeting with the participant, to determine whether they would like to meet fellow study participants. At the group meeting participants can discuss their own walking experiences after stroke with other stroke survivors. Both the qualitative study and the systematic review showed the importance of social support in helping motivate stroke survivors take part in physical activity. Therefore, peer support would be facilitated by organising the group meeting. Meetings would be held between four and eight weeks after study inclusion, dependent on when participants are recruited into the study. Meetings would be held informally, be facilitated by the researcher (SN) and participants would be encouraged to keep in touch with each other to maintain motivation and provide peer support. Meetings would be held within the Clinical Research Facility at the Royal Infirmary of Edinburgh. To encourage attendance travel expenses will be reimbursed and tea and coffee provided for the participants.

7.7. Final outcome measures

After the final week of the behaviour change intervention (week 12) participants will be asked to return to the Clinical Research Facility. At this visit the SN (or a Clinical

Research Facility nurse) will again perform the secondary outcome measures with each participant and retrieve the activPAL™ accelerometer and pedometer. The activPAL™ will have been worn the previous 7 days for 24hours a day. If desired, participants will be able to keep the pedometer to continue to monitor their walking and daily step counts. Physical activity data will be downloaded from the activPAL™ accelerometer and compared with baseline. Similarly secondary outcome measures will be compared to baseline and any changes in the measurements noted.

7.8. Conclusion

This chapter has detailed each of the key components of the behaviour change intervention and the rationale for their inclusion in the intervention. Attempts have been made to ensure that the behaviour change intervention would be easy to follow for participants. All aspects of the intervention have a strong grounding in theory and have embedded the knowledge obtained from the first three studies of this PhD. The following chapters will detail the testing and refining of this behaviour change intervention with stroke survivors.

CHAPTER 8 Two stage trialling of the behaviour change intervention to increase physical activity, predominantly walking, after stroke

After the development of the behaviour change intervention, the next stage was to test the feasibility and acceptability of the intervention with stroke survivors. The original plan was to test the intervention in an uncontrolled pilot of 10 participants, followed by a controlled pilot of 20 participants. These two pilot studies would determine the feasibility and acceptability of the intervention within the stroke population. However, due to a number of factors (discussed in section 8.5.2), recruitment into the uncontrolled pilot study was low. Therefore, it was decided a second round of recruitment was necessary. The first round of recruitment was undertaken between (08/07/2012 and 09/08/2012) and aimed to recruit 10 stroke survivors. Due to low recruitment and retention, changes to the behaviour change intervention protocol were made and a second round of recruitment undertaken between (28/01/2014 and 16/04/2014). This second round of recruitment was undertaken almost two year later due to a period of maternity leave. Both uncontrolled pilots of the behaviour change intervention aimed to determine the feasibility and acceptability of the behaviour change intervention in stroke survivors.

8.1. Abstract

INTRODUCTION: Behaviour change interventions have been shown to increase physical activity in both the general and diseased populations. This body of work

investigated the feasibility and acceptability of a behaviour change intervention designed to increase physical activity after stroke. The aim was to recruit stroke survivors to complete a 12 week behaviour change intervention designed to increase physical activity through walking.

METHODS: The original methodology for the behaviour change intervention can be found in section 7.5. Two rounds of recruitment into the intervention were undertaken at separate time points. Amendments to the study protocol were undertaken between each round of recruitment to improve the recruitment and retention of participants into the study. The feasibility and acceptability of the intervention to stroke survivors were analysed after each round of recruitment.

RESULTS: During the first recruitment period, 12 eligible stroke survivors were approached to participate in the behaviour change intervention. Six of the twelve eligible stroke survivors agreed to participate. The pedometer did not detect the required 70% of steps in 4/6 potential participants during the screening test (a two minute walk test). Therefore, these potential participants were unable to be recruited into the behaviour change intervention. Two participants were recruited, with one participant being withdrawn from the study during week one. The one remaining participant (male; 66years) completed the full 12 week behaviour change intervention increasing their step count by 14.3% [4,653 steps] (from 27,944 steps at week one to 32,597 steps by week twelve).

During the second recruitment period, 23 stroke survivors were approached to participate in the behaviour change intervention. Nine stroke survivors agreed to

complete the behaviour change intervention. Six participants withdrew or were withdrawn from the study. Therefore, only three participants completed the full 12 week behaviour change intervention [2/3 (66%) male; mean age 79 years SD= 4.32 years]. All three participants had had an ischaemic stroke.

CONCLUSIONS: Recruitment was improved in the second round of the behaviour change intervention, with 9/23 participants agreeing to participate. However, there was a higher than expected dropout rate of 67%.

As participation in physical activity is fundamental after stroke, further research is required. Based on the results of only three participants we were unable to fully determine the feasibility and acceptability of the behaviour change intervention. This study has shown that one intervention does not fit all, and the use of a monitoring device and structured behaviour change intervention may not suit all stroke survivors. Further research is required to discover the most feasible and acceptable intervention for stroke survivors to help increase physical activity in the long term.

8.2. Introduction

To help reduce these possible complications post stroke and increase physical activity a behaviour change intervention was developed. The behaviour change intervention aims to gradually and systematically increase walking in the first three months after discharge from hospital after acute (first ever or recurrent) stroke.

Before trialling whether the behaviour change intervention could increase physical activity after stroke (through a randomised controlled trial) it was essential to determine if the intervention was both feasible and acceptable to stroke survivors. As

this was a newly developed behaviour change intervention, it was essential to determine if all aspects of the intervention were easily followed by stroke survivors and whether the intervention could be successfully implemented or if changes to the intervention design were required.

8.3. Methods

Ethical approval was obtained for this study from the South East Scotland Research Ethics Committee 01 on the 13th of June 2012. A copy of the ethical approval can be found in appendix 7. Additional approval from the ethics committee was sought to make amendments to the protocol and carry out a second round of recruitment.

Ethical approval was obtained for the second round of recruitment from the South East Scotland Research Ethics Committee 01 on the 16th of December 2013. A copy of the ethical approval can be found in appendix 8.

8.3.1. Recruitment

Patients admitted with an acute stroke (first-ever or recurrent) who were ready for discharge from six stroke units in Edinburgh and the Lothians (two acute, three rehabilitation and one mixed rehabilitation/acute unit) were identified in consultation with clinical teams, between 09/07/2012 and 09/08/2012 (recruitment round one) and between 28/01/14 and 16/04/14 (recruitment round two). The aim of each round of recruitment was to recruit 10 participants into an uncontrolled pilot study of the behaviour change intervention. The recruitment window for round one was short (four weeks) due to impending maternity leave (see section 8.5). This ensured that study participants had completed the 12 week intervention before maternity leave

began. The second round of recruitment lasted for three months, and was again cut short due to impending maternity leave. However, nurses from the Clinical Research Facility at Edinburgh Royal Infirmary were trained in undertaking the measurements and phone calls with study participants to allow recruitment to continue as long as possible to allow more participants to be recruited. A copy of the participant information sheet and consent form for round one of recruitment can be found in appendix 9. A copy of the participant information sheet, consent form and updated booklets for round two of recruitment can be found in appendix 10.

8.3.2. Feasibility and acceptability of the intervention

To determine the feasibility and acceptability of the behaviour change intervention data were collect in seven key areas:

1. The proportion of eligible stroke survivors that were approached to take part in the intervention.
2. How many eligible stroke survivors agreed to participate.
3. The number of participants who withdrew from the study and the reasons for withdrawal.
4. The numbers of missing step counts in participant's step diaries due to either pedometer "failure" or participants forgetting to record their steps.
5. The duration of each telephone call and meeting with each participant.
6. The participant attendance at a group meeting.
7. The responses from the participant's feedback form.

Collecting these data helped to establish the feasibility and acceptability of the intervention with stroke survivors, and highlight any areas of the intervention that required alteration.

8.4. Results for round one of recruitment

8.4.1. Recruitment

During the four week recruitment period, 12 stroke survivors were invited to participate in the intervention of whom 6/12 (50%) agreed. The pedometer did not detect the required 70% of steps for 4/6 (66%) of these potential participants during the screening test (a two minute walk test). Therefore these potential participants were unable to proceed with the study and take part in the behaviour change intervention. The remaining two participants were recruited into the behaviour change intervention as the pedometer detected 70% (or more) of their steps during the screening test.

8.4.2. Participant demographics

One participant was female, one was male and participants were aged 76 and 66 years respectively. Both participants had ischaemic strokes and the time since their strokes were 19 and 36 days. Neither participant had residual gait abnormalities, nor used a walking aid. One participant had mild expressive dysphasia, and the other participant had a homonymous hemianopia and visual inattention. Neither of these conditions excluded their participation in the study.

8.4.3. Study participation

During the first week of the intervention, one participant withdrew from the study. The participant had become very confused and found the study too much. The participant had decided not to wear either the pedometer or the accelerometer during this time. On discussion with the participant, their family and the research team it was decided that this participant would be withdrawn from the study with no further follow-up.

8.4.4. Intervention results

The remaining participant completed the full 12 week behaviour change intervention. Figure 11 details the participant's weekly step counts (as read from the pedometer) compared with their weekly step targets set by the researcher and participant. Figure 11 shows that the participant's step count at week one was 27,944 steps and by week 12 of the intervention their step count had risen to 32,597 steps. This equates to an increase of 4,653 steps (16.7%) over the 12 week intervention period. As can be seen from figure 11, although there was an overall increase in step count the participants steps did vary each week. The participant developed gout at approximately week three of the intervention, accounting for the drop in weekly step count. During week nine the participant went on holiday and reported doing a lot of sightseeing, accounting for this peak in step count. The participant achieved (or walked greater than) the step targets on seven weeks of the behaviour change intervention.

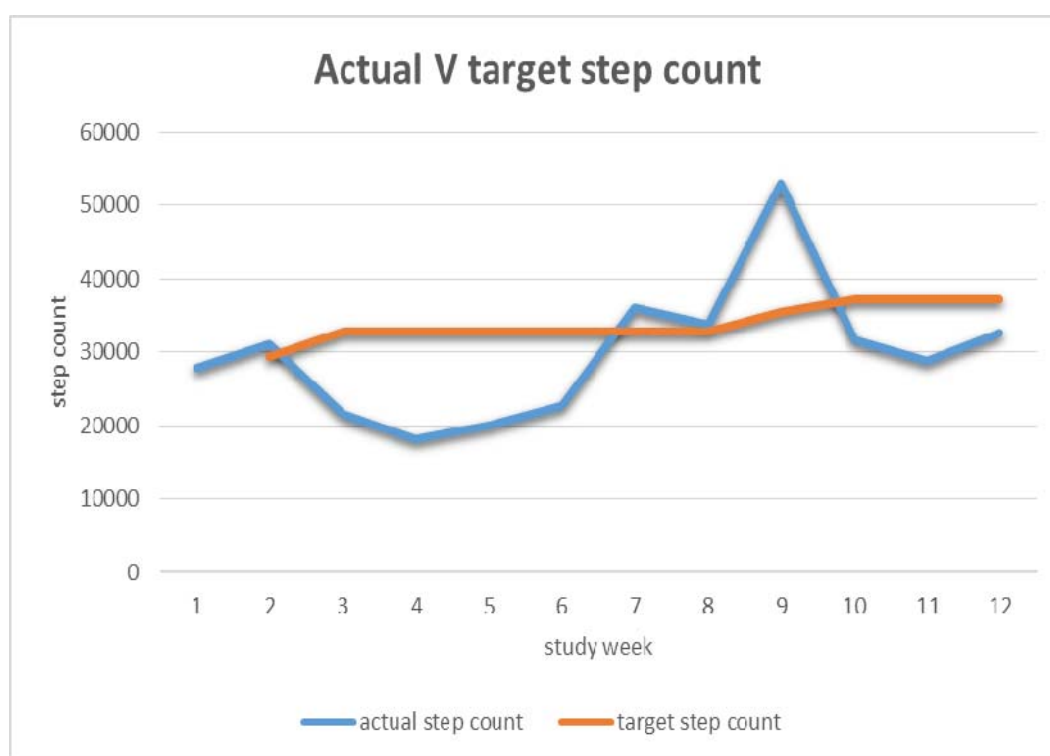


Figure 11: Actual (pedometer) and target step counts over the study period

Results from the secondary outcome measures are shown in table 5. SPPB, EQ-5D-5L and HADS scores improved, while activities of daily living and fatigue scores remained similar.

Table 5: Secondary outcome measures from weeks 1 and 12 of the behaviour change intervention

Secondary outcome measure	Week 1	Week 12
Short physical performance battery (each score is 0-4: 0 being unable to complete and 4 being the best. Summary score ranges from 0-12 and is total of previous 3 scores) <ul style="list-style-type: none"> chair stands score tandem balance score gait speed score summary score 	3 4 4 11	4 4 4 12
The Nottingham extended activities of daily living (range 0-22, higher score =greater independence)	21	20
EQ-5D-5L (each score is 1-5: 1 indicating no problem and 5 indicating extreme problem. Summary score is 0-100 with 0 being worst health imaginable and 100 being best) <ul style="list-style-type: none"> Mobility score Self-care score Usual activities score Pain score Anxiety score Summary score 	1 1 2 1 3 90	1 1 1 1 1 90
Hospital Anxiety and Depression Scale (each score range is 0-21: 0-7 indicates normal, 8-10 indicates borderline depression or anxiety and 11-21 indicates depression or anxiety) <ul style="list-style-type: none"> Anxiety score Depression score 	7 13	2 4
Fatigue Assessment Scale (range from 10-50, 10-21 indicates no fatigue, 22-34 indicates fatigue, >= 35 indicates extreme fatigue)	23	24

The primary outcome measure of physical activity (specifically focussing on step count) was obtained using the activPAL™ accelerometer. The study participant wore

the activPAL™ accelerometer during week one and week twelve of the behaviour change intervention. There were technical issues downloading the data from accelerometer and therefore there were no data from the activPAL™ for week one of the intervention. During the final week, the accelerometer stopped working after three days and therefore the complete week's data were not available. Data from the activPAL™ provided two complete 24 hours periods as detailed in figure 12. In the first 24 hours period the participant walked 4,132 steps and in the second 24 hours period the participant walked 5,770 steps.

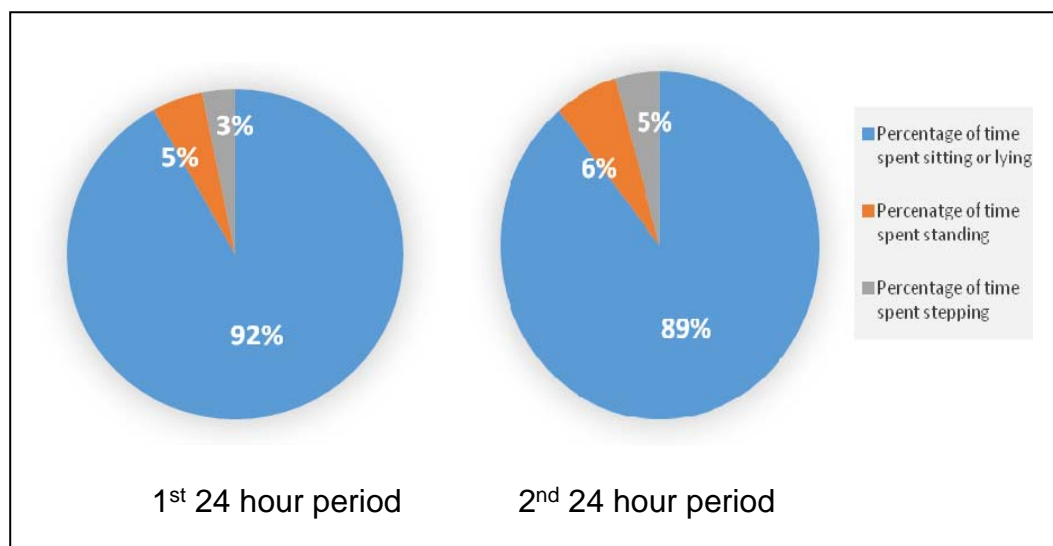


Figure 12: Study participant's week 12 activPAL™ data

8.4.5. Feasibility and acceptability data

Twelve stroke survivors were approached to take part in the study. Six of the twelve stroke survivors (67% male) declined to participate in the behaviour change intervention; 3/6 (50%) felt the study would be “too much” for them and did not wish to participate, 1/6 (17%) participant felt they “already did enough physical activity” and 2/6 (33%) participants gave no reasons for declining to participate. The remaining 6/12 stroke survivors were recruited into the behaviour change intervention. The 4/6 participants who were unable to participate in the study after the screening test reported feeling “disappointed”. These participants also reported that they felt “the study was a good idea” and that they were “keen to try and increase their physical activity when they returned home from hospital”.

As discussed, one participant dropped out of the study due to confusion. Although this participant had the capacity to consent and understood what the intervention asked of them, once enrolled the participant found the study was “too much” and were subsequently removed. The remaining participant completed the whole intervention. For the participant who completed the intervention their step diary was completely filled in and with no missing data. As only one participant completed the intervention, the group session with study participants (between weeks four and eight) was not conducted. This was explained to the study participant who had previously expressed an interest in attending the group session.

Over the course of the 12 week intervention the participant received five telephone calls from the researcher to discuss study progress, provide motivation, collect the previous week’s step counts and set the following week’s step target. The mean duration of these telephone calls was 9 minutes (SD=1.4minutes).

The participant completed the feedback form at the end of the intervention. The participant stated feeling the study was “just the right length”, it was “very easy” to read and put on the step counter, the booklet was “very easy” to follow and that the frequency of the telephone calls from the researcher were “about right”. The participant graded their satisfaction with the intervention as 9/10. The participant also made additional comments reporting it would be “easy to lie to make sure you met the step target” and that they “did not really look at the step targets very frequently” and “just tried to increase their step count regardless of the intervention”. These statements were valuable in determining the acceptability of the intervention.

8.5. Discussion from round one of recruitment

8.5.1. General

Results from this initial uncontrolled pilot study of the behaviour change intervention indicate the difficulties that surround undertaking behaviour change feasibility and acceptability studies. This pilot study was not powered to determine the effectiveness of the intervention. However, this study was the first stage in determining the feasibility and acceptability of the behaviour change intervention within the stroke population.

8.5.2. Recruitment

Recruitment into the behaviour change intervention was low. Low recruitment may have been due to several factors including the recruitment window being very short (four weeks) due to time constraints. Recruitment for the pilot study had been postponed to allow extra time for the accelerometer from the Culture Lab at

Newcastle University to be developed. It was envisaged that the accelerometer would be more accurate at detecting step count than the OMRON-HJ-113-E pedometer. However, as the accelerometer was not developed for use in the uncontrolled pilot study recruitment had to begin later than planned using the OMRON-HJ-113-E pedometer.

The OMRON-HJ-113-E pedometer did not detect adequate steps for four of the six participants willing to participate in the behaviour change intervention. This was a higher than expected rate of study exclusion. Previous data, using the OMRON-HJ-113-E pedometer, indicated that these pedometers would detect greater than 70% of steps in approximately 60% of stroke survivors (Carroll et al., 2012). However, only 33% (2/6) of the stroke survivors willing to take part in the behaviour change intervention had step counts greater than 70% during the screening test. This excluded a large proportion of interested stroke survivors from taking part in the behaviour change intervention. Having a large proportion of stroke survivors walking more slowly than previously expected, may be due to the different nature the behaviour change interventions to the previous study (Carroll et al., 2012). The previous study was a short, one-off observational study which may have been perceived as less of a burden to participants compared with a 12 week behaviour change intervention (Carroll et al., 2012). Therefore, those who wished to participate in the behaviour change intervention may have been those who were more severely disabled by their stroke, and therefore had slower walking speeds.

8.5.3. Feasibility and acceptability

Only one participant completed the behaviour change intervention. This participant reported that he felt the benefit of taking part in the intervention. Although step count was variable each week (figure 13) the participant's pedometer data showed an overall increase in walking from 27,944 steps to 32,597 steps (an increase of 16%) over the course of the intervention. Whether this increase was a result of the intervention, or just part of stroke recovery, remains unclear. The participant stated they felt the study was "just the right length", it was "very easy" to read and put on the pedometer, the booklet was "very easy" to follow and that the frequency of the telephone calls from the researcher were "about right". The participant graded their satisfaction with the intervention as 9/10. These results indicate that the participant found the intervention both feasible and acceptable, but with only one participant completing the full intervention, data are inconclusive. To be able to fully analyse the intervention's feasibility and acceptability more data were required. Therefore, instead of proceeding to a controlled trial it was deemed necessary to conduct a second round of recruitment into the uncontrolled pilot study.

8.5.4. Proposed protocol changes

In an attempt to improve recruitment, two key amendments were made to the behaviour change intervention protocol before the second round of recruitment was undertaken.

- 1. Participants, in whom the pedometer did not detect 70% of steps during the screening, would be recruited into the intervention. These participants would record daily minutes of walking (both inside and**

outside) instead of being excluded from the study. This record would be the ‘feedback’

Initial findings showed 4/6 (67%) participants who wished to take part in the study were unable to do so due to the pedometer not detecting over 70% of their steps. This was considered as an unacceptably high number of participants to be excluded from the study. This was especially apparent, as these stroke survivors had shown a keen interest in participating in an intervention to increase physical activity, but had to be excluded due to the pedometer. Therefore an alternative method of feedback was necessary for these stroke survivors. As there was no alternative electronic device available, self-monitoring of physical activity would need to be utilised. Diaries have been used previously to monitor physical activity after stroke by asking participants to note the tasks they have carried out in the past 15 minutes (Vanroy et al., 2014). Therefore, participants would be encouraged to monitor, as often as possible, the minutes they had spent walking and whether this walking was indoors or outdoors. It was felt asking participants to record both indoor and outdoor walking would make it easier for the participant to monitor their walking throughout the day.

By including this slower walking group of stroke survivors there would now be two group of participants taking part in the second round of the uncontrolled pilot study of the behaviour change intervention. **Group one)** would record both their daily step count from the pedometer and the minutes spent walking indoors and outdoors each day. **Group two)** would only record the minutes they spend walking indoors and minutes spent walking outdoors each day. All outcome measures and components of the intervention were the same between the two groups. We were unable to return to the initial participants, who could not be included during the first round of

recruitment, as these participants were now approximately 18 months post stroke. At this stage in stroke recovery walking may have greatly improved and may not be a true representation of their initial post stroke mobility.

2. Weekly steps targets were increased from 5% to 10% increments each week (as long as the previous week's target had been met).

The second amendment to the behaviour change intervention protocol was to increase the weekly step targets from 5% to 10%. The original 5% increase in weekly step target was based on a previous study of 240 sedentary older women (>70 years) (McMurdo et al., 2010). This study had a step increase of baseline + 20% of steps walked each month of the six month intervention. Results indicated statistically significant increases in walking at the end of the intervention, however walking returned to baseline at six months post intervention (McMurdo et al., 2010). Since the first round of recruitment, a 12 week behaviour change intervention had been published reporting increases in physical activity in 79 low physically active men and women (Fitzsimons et al., 2012). The aim of the 12 week behaviour change intervention was to increase average daily step count by 3,000 steps above baseline value on at least five days of the week by week six and maintain this to week 12 (Fitzsimons et al., 2012). These increases in step target were much greater than the earlier behaviour change intervention in sedentary older women (McMurdo et al., 2010) (Fitzsimons et al., 2012). Results from this study showed increases in steps between: pre-intervention ($M = 6941$, $SD = 3047$) and 12 weeks ($M = 9327$, $SD = 4136$), $t(78) = -6.52$, $p < 0.001$, $d = 0.66$; pre-intervention and 24 weeks ($M = 8804$,

SD = 4145), $t(78) = -4.82$, $p < 0.001$, $d = 0.52$; and pre-intervention and 48 weeks (M= 8450, SD = 3855), $t(78) = -4.15$, $p < 0.001$, $d = 0.44$ (Fitzsimons et al., 2012). Moreover, these results showed increases in physical activity up to 48 weeks post intervention (Fitzsimons et al., 2012). This second behaviour intervention was more successful in increasing and maintaining step counts than the earlier study. Therefore, it was decided to increase the behaviour change intervention's step targets from 5% to 10% with the aim of providing longer term improvements in walking and overall physical activity.

8.6. Recruitment round two

8.6.1. Methodology

The second round of recruitment again aimed to recruit a further 10 stroke survivors to undertake the updated behaviour change intervention. This would provide sufficient data on feasibility and acceptability of the intervention. The main methodology for the behaviour change intervention has been previously detailed in chapter 7. The main change to the methodology for the second round of recruitment was that there would now be two participant groups running concurrently. This is detailed in figure 13.

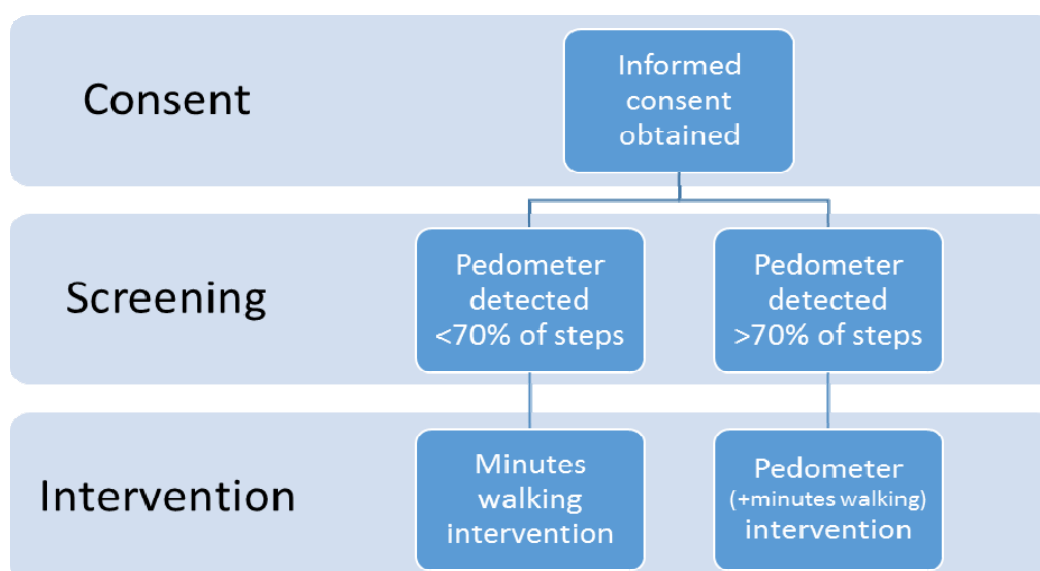


Figure 13: Recruitment plan for the amended behaviour change intervention

Once recruited into the intervention both groups followed the same protocol of telephone calls and visits from the researcher. However, each group would have a separate group meeting to discuss how they were finding all aspects of the behaviour change intervention.

8.7. Results for the second round of recruitment

8.7.1. Recruitment

23 stroke survivors were approached to participate in the behaviour change intervention between 28/01/14 and 16/04/14. Recruitment is detailed in figure 16.

7/23 (30%) stroke survivors approached to participate in the behaviour change intervention declined to participate, and a further 7/23 (30%) were unable to be recruited. Potential participants were unable to be recruited because they were either boarded onto hospital wards out with study recruitment (2/7) or they were discharged

from hospital less than 24 hours after initially being approached by the researcher to participate in the study (5/7). Of the nine participants recruited to the intervention 6/9 (67%) subsequently withdrew or were withdrawn. There were numerous reasons why participants did not complete the 12 week behaviour change intervention. Of the participants who dropped out of the intervention two reported that they had “too much on their plate” since returning home from hospital. One of these participants had many social issues since their stroke. This participant had lost their job as a result of their stroke and was having difficulties sorting out benefits since returning home. The second participant had double cataracts and was attending hospital appointments for this. Due to this, she decided the study was an added burden that she did not have time for. A third participant withdrew in the second week of the study as they found it very difficult to remember to wear their pedometer each day and to record their steps each night in their diary. Attempts were made to help this participant stay in the study e.g. asking carer to help participant with pedometer every morning and night. However, the participant still regularly did not record steps and subsequently withdrew from the study. Two participants became ill during their first weeks home from hospital and were subsequently removed from the study. One participant developed gout and was re-admitted to hospital. On returning home from hospital this participant felt the study was now “too much” for them and withdrew. Another participant was re-admitted to hospital after falling and breaking their hip. After consultation with the participant and study team it was deemed the participant’s fall was not a direct cause of participation in the study (the participant had gone to the toilet through the night and had fallen). This participant was subsequently withdrawn from the study. A third participant became acutely confused

shortly after recruitment into the study. Subsequently this participant did not return home from hospital during the study period and the research team felt it was necessary that they should be withdrawn from the study. This second round of recruitment is detailed in figure 14.

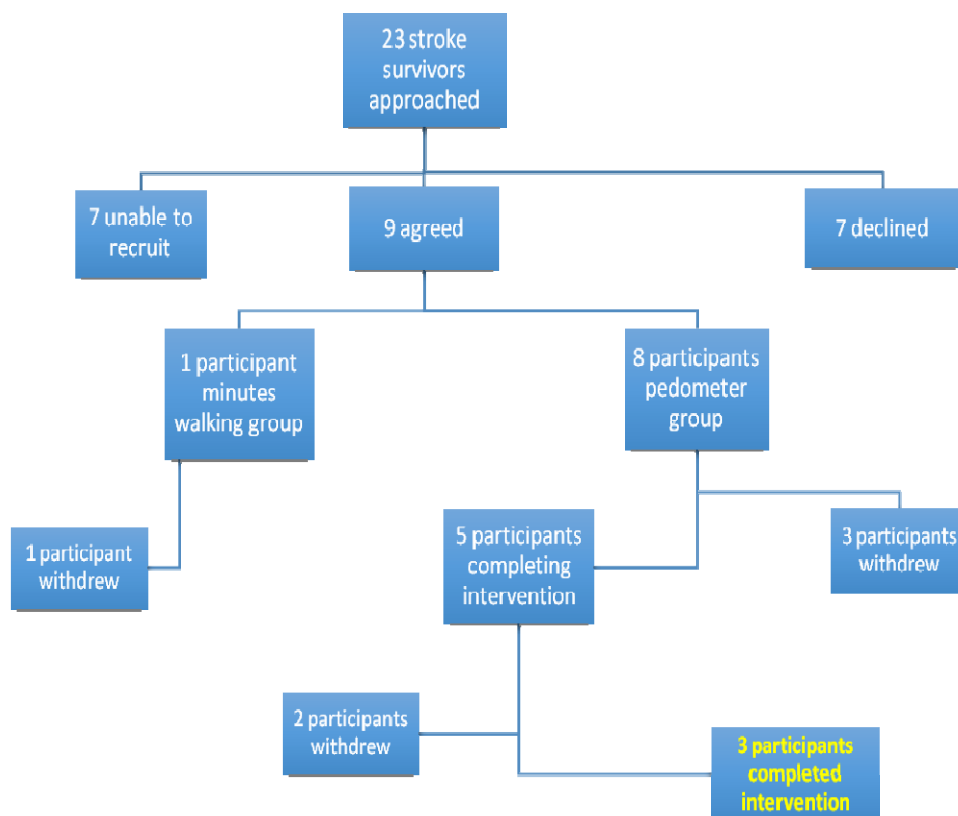


Figure 14: Second round of recruitment to the behaviour change intervention

8.7.2. Participant demographics

Three participants completed the full 12 week behaviour change intervention as part of the pedometer group (Group one). 2/3 (67%) of the participants were male. Participant mean age was 79 years (SD= 4.32 years). All three participants had ischaemic strokes. 2/3 (67%) of the participants had no residual gait abnormality,

while the remaining participant had shuffling gait. Two participants used one stick for outdoor mobility. The remaining participant used a delta walker for outdoor mobility, later progressing to using just one stick. One participant had a residual left sided weakness and one participant had left sided lower leg nerve palsy from a previous condition. None of the participants suffered visual or motor neglect, dysphasia or dyspraxia.

8.7.3. Physical activity results

All three participants completed the full 12 week intervention, recording daily pedometer step counts and estimated daily minutes spent walking both indoors and outdoors. Figure 15 details the weekly pedometer readings for all three participants. From week one to week twelve participant one increased their step count from 6,080 to 24,364 steps per week, an increase of 400.1%. Step count for participant two was over six times greater by the end of the intervention, increasing from 2,374 to 15,660 steps (an increase of 659.6%) while step count for participant three increased from 4,214 to 7,947 steps (an increase of 188.6%) by the end of the intervention.

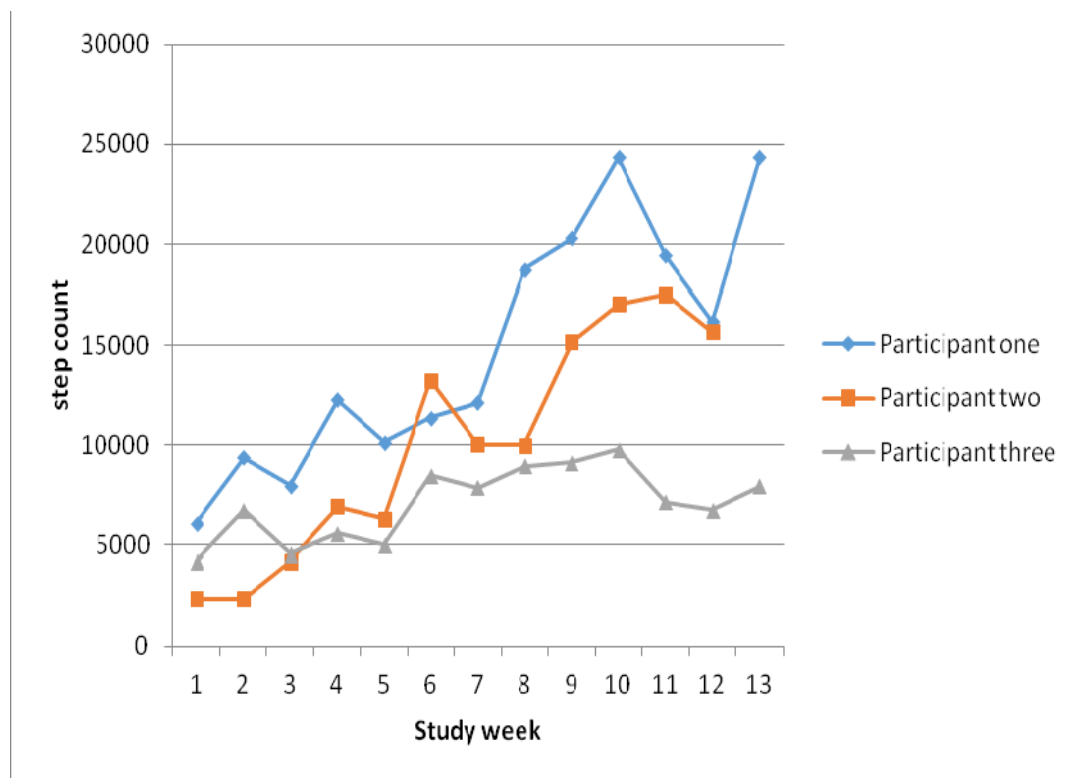


Figure 15: Weekly pedometer step counts for each participant

Figure 16 details the weekly *total* minutes (*indoor minutes* + *outdoor minutes*) each participant estimated they walked. From weeks one to twelve participant one estimated their total minutes spent walking increased from 220 to 435 minutes (an increase of 197.7%). Participant two estimated their total minutes spent walking increased from 255 to 400 minutes (an increase of 156.9%) from week one to twelve, while participant three estimated their total minutes spent walking dropped from 230 to 195 minutes per week (a reduction of 15.2%). However, figure 18 shows that the weekly estimate for participant three peaked at week six where it was estimated they walked a total of 525 minutes (an increase, from baseline, of 228.3%).

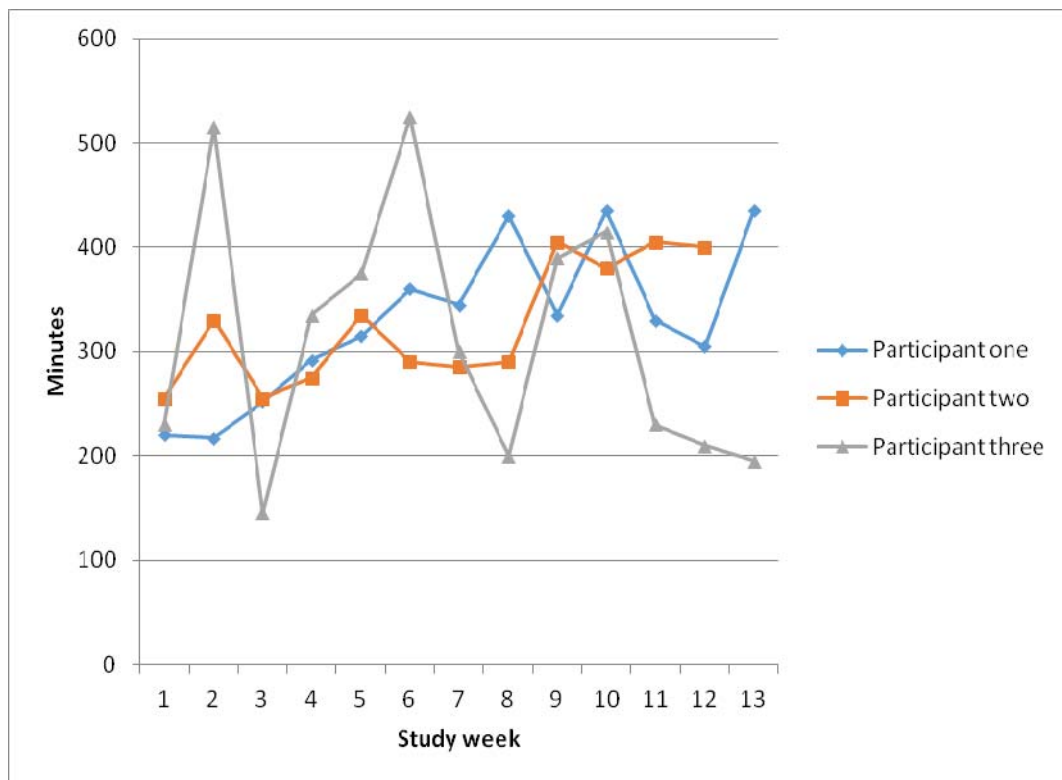


Figure 16: Weekly estimates (indoor + outdoor) of minutes spent walking

Figures 17-19 compare each participant's weekly step targets with actual pedometer step counts. Participant three asked for their step target to remain constant from week 10 (figure 19). This was due to the participant feeling that they would be unable to walk any further than they were already achieving. Therefore, participant three did not want the target set any higher in case this would discourage her as she was unable to meet the target.

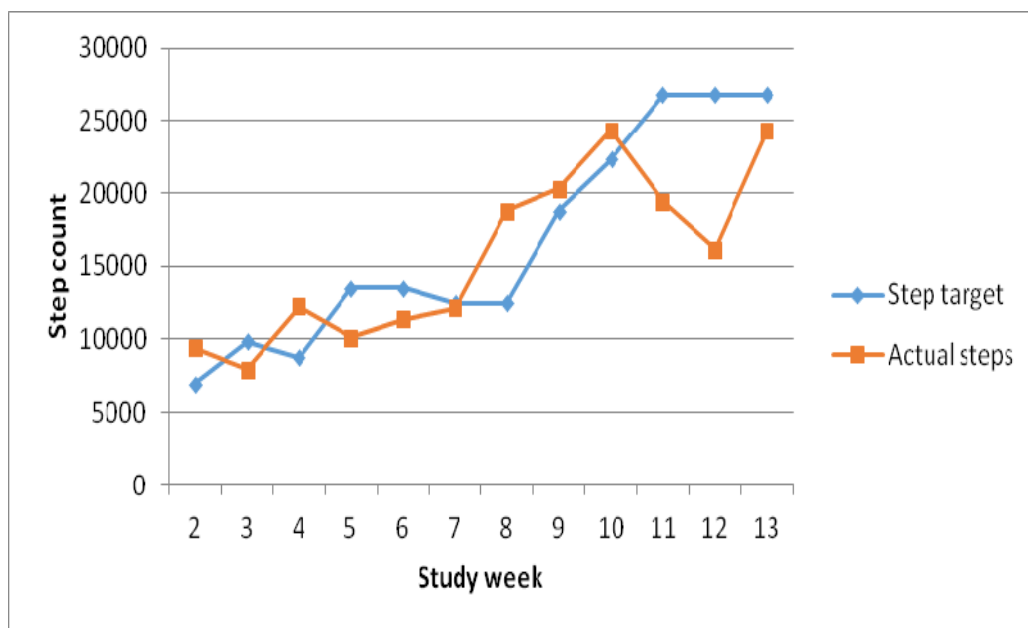


Figure 17: Actual versus target step count for participant one

Step targets for participant one increased from 6,960 to 26,790 over the course of the intervention. Participant one achieved (or walked greater than) their step targets on five weeks of the behaviour change intervention.

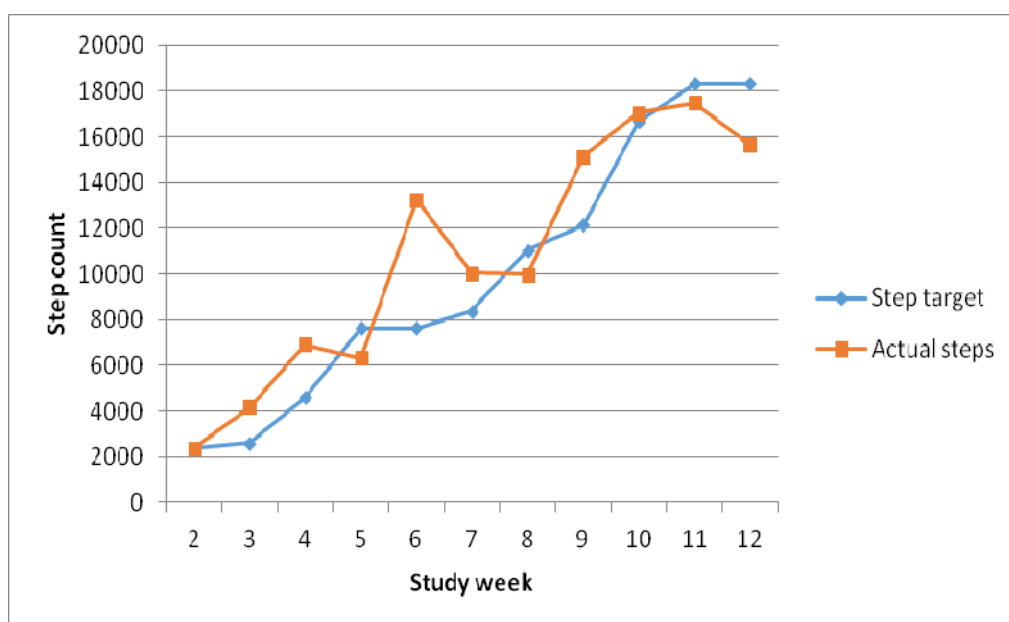


Figure 18: Actual versus target step count for participant two

Step target for participant two increased from 2,374 to 18,336 steps over the course of the intervention. Participant two achieved (or walked greater than) their step targets on seven weeks of the behaviour change intervention.

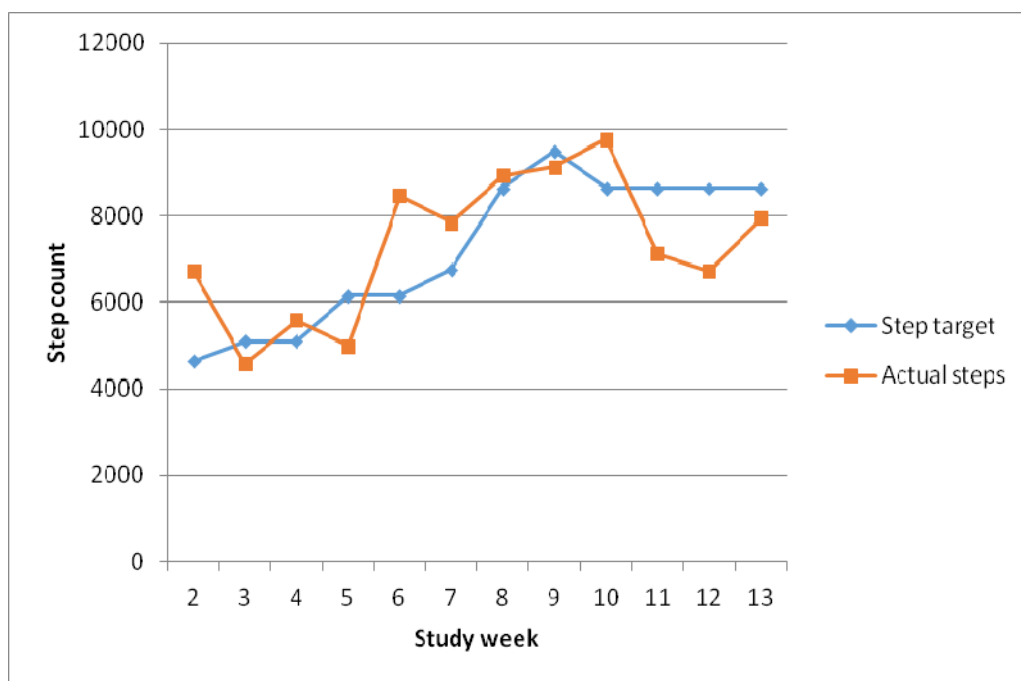


Figure 19: Actual versus target step count for participant three

Step targets for participant three increased from 4,635 to 9,498 steps over the course of the intervention. Participant three achieved (or walked greater than) their step targets on six weeks of the behaviour change intervention.

8.7.4. Primary and secondary outcome measure results

All three study participants wore the activPAL™ accelerometer during week one and twelve of the behaviour change intervention. All physical activity data from the

activPAL™ accelerometers were successfully downloaded. The pedometer and activPAL™ step counts for week one are detailed below in table 6.

Table 6: Week one activPAL™ versus pedometer step counts for each participant

Participant	Total pedometer recorded steps (week one)	Total activPAL™ recorded steps (week one)
1	6,080	19,598
2	2,374 (3 days of pedometer data missing)	17,900
3	4,214	9,894

The activPAL™ also recorded the users average time spent sitting, lying and stepping during each 24 hour period. Figures 20-22 detail each participant's physical activity breakdown over weeks one and twelve of the behaviour change intervention.

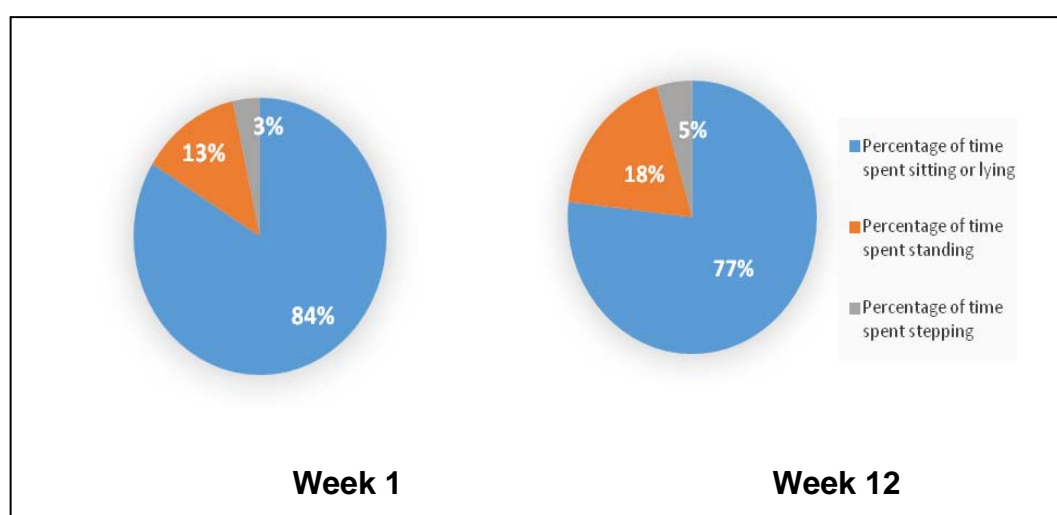


Figure 20: Weeks one and twelve activPAL™ data for participant one

Week 12 activPAL™ data for participant one showed a 7% reduction in time spent sitting or lying compared with week one. Participant one demonstrated increases in both time spent standing and stepping by 5% and 2% respectively.

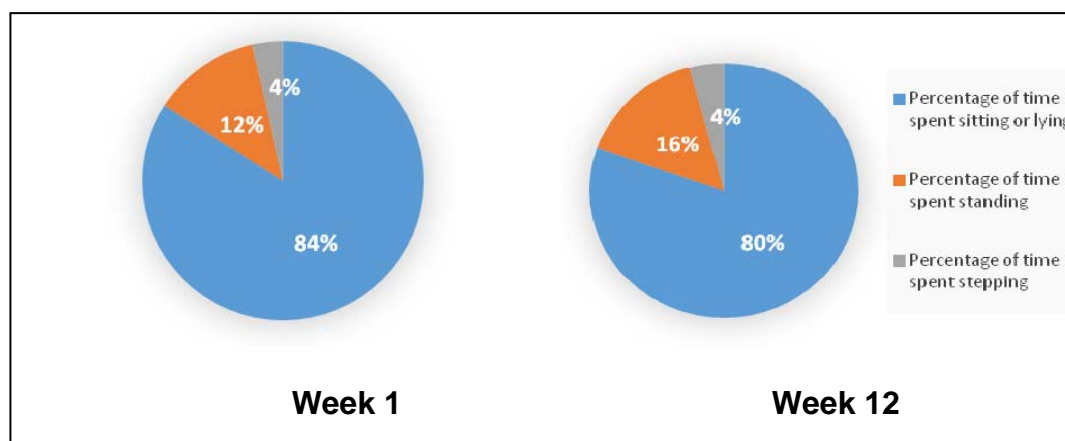


Figure 21: Weeks one and twelve activPAL™ data for participant two

Week 12 ActivPAL™ data for participant two shows a 4% reduction in time spent sitting or lying compared with week one. Participant two had an increase of 4% in time spent standing, however time spent stepping remained the same.

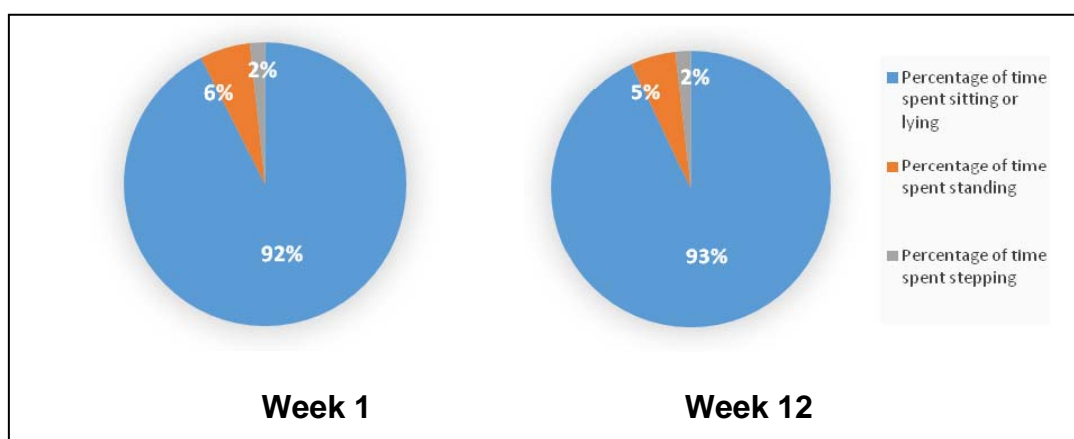


Figure 22: Weeks one and twelve activPAL™ data for participant three

Week 12 activPAL™ data for participant three showed a 1% increase in time spent sitting or lying compared with week one. There was a reduction in time spent standing by 1% and time spent stepping remained the same. However, this participant's pedometer data showed an increase in their step count from 4,214 steps (week 1) to 7,947 steps by the end of the intervention (week 12). This was an increase in steps of 88% over the 12 weeks.

All three participants completed all the secondary outcome measures at week one and week 12 of the behaviour change intervention. Results of the secondary outcome measures can be seen in table 7.

Table 7: Results of secondary outcome measures for all three study participants

Secondary outcome measure	Participant one		Participant two		Participant three	
	Week 1	Week 12	Week 1	Week 12	Week 1	Week 12
SPPB (each score is 0-4: 0 being unable to complete and 4 being the best. Summary score ranges from 0-12 and is total of previous 3 scores) <ul style="list-style-type: none"> • Chair stands score • Tandem balance score • Gait speed score • Summary score 	1	3	1	2	0	0
	3	4	3	2	2	3
	3	4	2	3	3	4
	7	11	6	7	5	7
NEADL (range 0-22, higher score =greater independence)	5	6	4	3	4	3
EQ-5D-5L (each score is 1-5: 1 indicating no problem and 5 indicating extreme problem. Summary score is 0-100 with 0 being worst health imaginable and 100 being best) <ul style="list-style-type: none"> • Mobility score • Self-care score • Usual activities score • Pain score • Anxiety score • Summary score 	2	2	2	2	2	2
	2	2	2	1	2	1
	2	2	2	2	2	2
	1	2	1	2	2	2
	1	1	1	1	1	1
	65	90	65	90	50	70
HADS (each score range is 0-21: 0-7 indicates normal, 8-10 indicates borderline depression or anxiety and 11-21 indicates depression or anxiety)						

• Anxiety score	1	2	1	0	0	0
• Depression score	2	3	0	1	6	5
FAS (range from 10-50, 10-21 indicates no fatigue, 22-34 indicates fatigue, >= 35 indicates extreme fatigue)	20	22	60	16	50	42

8.7.5. Feasibility and acceptability data

Twenty three stroke survivors were approached to participate in the behaviour change intervention. Of the 23 stroke survivors given the participant information sheet, seven declined to participate (3/7 did not wish to participate, 1/7 reported they felt their stroke was not severe enough and the remaining 3/7 gave no reason for declining). A further 7/23 stroke survivors were unable to be recruited due to 2/7 boarding to wards out with the recruitment wards and 5/7 were discharged from hospital less than 24 hours after initially being approached to take part in the study. Only 9 of the 23 participants approached agreed to participate in the behaviour change intervention and of these only 3/9 (33%) completed the full 12 week behaviour change intervention. Three participants withdrew or were withdrawn due to ill health and three withdrew because they found the intervention was 'too much for them'.

All three participants, who completed the whole behaviour change intervention, reported that they felt the study was “just the right length”. Two of the three participants reported they found recording the time they spent walking each day as either “very easy” or “quite easy” while the remaining participants reported recording time spent walking as “very difficult”. This participant reported using the

pedometer to record walking was easy but they found it very difficult to accurately record the minutes they spent walking indoors and outdoors. All three participants reported finding the booklet “very easy” to follow and that the frequency of the telephone contact from the researcher was “about right”. Two of the three participants rated their overall satisfaction with the intervention as a 10/10 (highly satisfied) and the remaining participant rated this as a 9/10. One participant’s additional comments included finding it difficult to record the minutes they spent walking indoors. This participant reported that they did not consider the small amounts of walking they did in the house as physical activity. One participant reported that they found it difficult to increase steps daily especially if they had other commitments during the week, as this would alter the amount of steps they were able to achieve.

Each participant received five telephone calls throughout the 12 week intervention. The mean time spent on these telephone calls was 8.5 minutes (SD= 7.7minutes). Two participants’ pedometers stopped working during the intervention, and therefore data were missing from their diaries for two days. One pedometer stopped working as the battery needed replacing and the other pedometer had shifted to a different function and the participant was unable to return to the normal setting.

During this second round of recruitment we were again unable to carry out a group session as per the protocol. The group session proved to not be feasible as there were only three participants taking part in the study over a prolonged time period. This meant that there were not enough participants at the same stage post stroke to make a group session worthwhile.

8.8. Discussion

8.8.1. General

Three stroke survivors successfully completed the 12 week behaviour change intervention. All participants stated they were satisfied with the intervention and found it helped them to monitor and increase their physical activity. However, results from the intervention varied. One participant's week 12 activPAL™ data showed a 1% increase in time spent sitting or lying. However this participants increase their walking over the intervention and showed improvements in their SPPB, EQ-5D and FAS, showing that there were improvements in the functional ability of this participant. All participants increased their step counts throughout the intervention, however their time spent stepping (according to the activPAL™) remained similar. This may be due to participants walking ability improving over the course of the intervention and therefore participants were walking faster and taking more steps in the same amount of time. Due to the small numbers in the study it is unclear whether this would be attribute to the intervention or the natural recovery process after stroke, where the stroke survivors are regaining strength in their walking and confidence in their walking ability.

8.8.2. Study recruitment

After the amendments were made to the study protocol, recruitment was higher than the first round with 9/23 (39%) participants recruited into the intervention. However, 6/9 (67%) stroke survivors who were recruited to take part in the study dropped out or were withdrawn within the first two weeks of the study (either due to ill health or feeling that the study was “too much” for them). A systematic review of randomised

controlled trials reported across multiple conditions reported dropout rates of typically around 18-20% (Wood et al., 2004). This rate is considerably lower than the rate found during this second round of recruitment (67%).

Stroke is a serious life changing event. When stroke survivors first return home from hospital they are likely to require a period of time to adjust to their new way of life. They may require time to adjust to what has happened to them and the changes that this may have led to both physically, socially and psychologically. Therefore, it may be more appropriate to begin the intervention further at a later point than discharge from hospital. However care needs to be taken that an intervention is not left too late, and stroke survivors have time to settle into the habit of a less physically active lifestyle. Therefore approximately one month post discharge from hospital may be an appropriate time to start the intervention. Interested stroke survivors would still be recruited at hospital discharge, but would not begin the intervention until at least one month post discharge. This would allow participants time to settle back at home and deal with any other issues arising from their stroke, before focusing on trying to increase their physical activity. By giving participants this period of time to adjust to their new way of life, prior to starting any intervention, would allow participant to adjust to any personal and/or social difficulties arising since their stroke. Having this acclimatisation period may allow participants to focus on participating in the behaviour change intervention and ultimately increasing their physical activity. However, delaying more than two months post discharge may be detrimental by allowing patients to settle into a routine of reduced physical activity at home.

8.8.3. Feasibility and acceptability

To decide whether the study is feasible and acceptable to stroke survivors it is essential to understand why the participants are finding the intervention “too much” for them to achieve. Is it because there were too many components of the intervention? Was the intervention too long? Or was it now that the participants had returned home from hospital they wanted to return to as normal as a life as possible and not participate in research? Responses from the participants who completed the intervention feedback indicated that they felt the study was the correct length and they were satisfied with the components of the intervention. All three participants managed to complete the intervention with minimal difficulties. Two of the participants had issues with their pedometers: one participant’s pedometer battery ran out and one participant had changed the setting on the pedometer and was unable to return to step counting mode. Once these issues had been resolved there were no further difficulties using the pedometers. Acceptability of the intervention to the stroke population is difficult to deduce from the data. Only 9/23 (39%) of stroke survivors approached agreed to take part in the intervention. However, a recent study has indicated that only 10% of stroke survivors will take part in clinical research (Busija et al., 2013). Moreover, 7/23 (30%) of stroke survivors approached to take part in the study were unable to be recruited due to study logistics (discharged less than 24 hours after receiving information sheet and being boarded out with study recruitment). Therefore, potentially interested stroke survivors were unable to be recruited.

8.9. Conclusion

Although recruitment was improved in the second round of the behaviour change intervention there was a higher than expected dropout rate of 67%. Participants who completed the intervention found it both feasible and acceptable and were able to increase their physical activity throughout the intervention. It is unclear if these increases were maintained once the intervention had ended. However, the high attrition and only 9/23 stroke survivors agreeing to take part in the study questions whether the intervention is acceptable to the wider stroke population.

This study has found that one intervention does not fit all, and the use of a monitoring device and structured behaviour change intervention may not be the best approach to increase physical activity for all stroke survivors. Determining if this intervention, in its current state, is feasible and acceptable to stroke survivors will be the focus of the final chapter. Possible changes and future directions of this behaviour change intervention will be discussed, to make this carefully and theoretically planned intervention more acceptable to the stroke population.

CHAPTER 9 General discussion and conclusions

This final chapter provides an overview of the previous chapters followed by a discussion of the key findings of this PhD thesis. The overall strengths and limitations of the programme of work are identified. The contributions from this programme of work to the field of physical activity after stroke are presented followed by the recommendations and directions for future research.

9.1. Overview of studies

This programme of work focussed on increasing physical activity after stroke. The overall aim was to develop and test a behaviour change intervention that would increase walking in stroke survivors. “Behaviour change interventions” are defined as co-ordinated sets of activities designed to change specified behaviour patterns. In general, these behaviour patterns are measured in terms of the incidence or prevalence of a particular behaviour in specified populations. Behaviour change interventions are primarily used to promote uptake and optimal use of effective clinical services, and to promote healthy lifestyles (Michie et al., 2011). The development of the complex behaviour change intervention as part of this thesis was done in accordance with the MRC framework for the design and evaluation of complex interventions (Craig et al., 2008). Development of the behaviour change intervention was theoretically driven by the use of the TDF (Michie et al., 2005). The TDF was used to identify key themes essential to altering and increasing the pattern of physical activity behaviour after stroke. These key themes were used to identify the fundamental BCTs that made up the components of the behaviour change intervention. BCTs are the “active ingredients” within an intervention designed to

change behaviour. They are recognisable, replicable and complex components of an intervention. A combination of BCTs can be used as part of a behaviour change intervention (Abraham and Michie, 2008).

In order to address the overarching aim of this thesis, six interlinking studies were conducted. The findings of each of these studies have been discussed in their respective chapters and will now be integrated to present the overall results of this programme of work.

9.2. Overall strengths and limitations

Justification for the study design adopted and the data collection methods that were followed for each study were sound. Care was taken to reduce any bias within the studies and previous literature was sought to determine best procedures for each study. Standardised and validated outcome measures were used when undertaking the uncontrolled pilot studies. It is believed that all the above measures enhanced the credibility of the findings of the individual studies, and thereby of the whole programme of work.

One potential key limitation of the systematic review searches (study one) was the large number of irrelevant titles and abstracts that were identified. There were no specific MeSH headings for barriers and facilitators and therefore key words were heavily relied upon. Key words included searching “barriers” and “motivators” as well as “facilitators” and “inhibitors” [see appendix one for full search strategies]. These searches led to large numbers of irrelevant titles being identified. However, search strategies are explicitly designed to be highly sensitive to allow as many potentially relevant studies as possible to be retrieved. Consequently the searches

retrieved a large number of records that did not meet the inclusion criteria. Although theoretical terms such as “outcome expectation” and “behaviour belief” could have been utilised instead, this may have reduced the number of citations identified resulting in potentially missing relevant studies. Therefore, the chosen methodology was deemed to be the most appropriate to ensure no relevant study titles were missed.

A potential key limitation for both of the uncontrolled pilot studies were the small sample sizes. These were a result of recruitment and retention problems faced throughout the uncontrolled pilot studies. Various attempts at improving recruitment within the available time scale did not yield the anticipated results. These low numbers have reduced the generalisability of the findings from the quantitative perspective and made determining the feasibility and acceptability of the intervention more challenging. Recruitment was not found to be a limitation in the qualitative study (study two) or the accelerometer validation study (study four). In terms of the qualitative research, data saturation was reached [following standard procedures] for the interviews which strengthened the qualitative study’s findings.

In hindsight, undertaking the collaboration with the Culture Lab at Newcastle University may have hindered recruitment to the pilot studies due to limiting the recruitment period. However, several other key factors may have limited the recruitment opportunities. These factors included the introduction of an Exercise after Stroke programme being rolled out on the main recruitment ward at the same time as recruitment began for the second uncontrolled pilot. This programme, introduced by Edinburgh Leisure, saw highly functioning stroke survivors being recruited into an exercise program design to increase physical activity after stroke. It

was decided that stroke survivors who were enrolled into the Edinburgh Leisure Scheme would be ineligible for recruitment to the pilot study, as participation may biased our findings. Participation in the Edinburgh Leisure Scheme would inadvertently increase physical activity and make it impossible to determine if the behaviour change intervention had been successful. Therefore, the potential recruitment sample for the uncontrolled pilot studies was reduced.

Recruitment problems forced changes in the design of this PhD. The original plan had been to carryout both an uncontrolled and a controlled pilot study to fully assess the feasibility and acceptability of the intervention. Along with the feasibility and acceptability, it was initially planned that the preliminary effects of the intervention could be evaluated. However, due to low recruitment in the initial uncontrolled pilot this was not possible.

A strength of this PhD was the systematic nature and theoretical underpinning of the work. This PhD has carried out in-depth exploration of the barriers and facilitators perceived by stroke survivors to the uptake of physical activity. This evidence has been elicited by multiple research methods (quantitative, qualitative and systematic review) and been published in key research journals. In addition both literature and theory have been considered in the development and initial evaluation of the behaviour change intervention.

9.3. Evaluation of the feasibility and acceptability of the intervention

The uncontrolled pilot studies were designed and carried out to determine the feasibility and acceptability of the behaviour change intervention. To be able to fully analyse feasibility and acceptability seven key areas were addressed (see section 7.8).

Each of these seven key areas were discussed in detail for each of the uncontrolled pilots in chapter 8 but their implications will now be discussed further.

The difficulties encountered while conducting these uncontrolled pilot studies question whether an intervention of this type is feasible to conduct with an ambulatory stroke population. Although the intervention was comprehensively and theoretically developed recruitment and retention into the studies were problematic. A total of 35 stroke survivors were approached to take part in either one of the uncontrolled pilot studies. Of these potential participants 15/35 (43%) agreed to participate. Of these participants seven withdrew for several varying reasons, and four were unable to take part due to the initial screening process (discussed in chapter 8). This was an unexpectedly high dropout rate for the studies. It is not clear why dropout rates were so high, and there were varied and valid reasons for each individual participant withdrawing from the studies. Three participants that found the study was “too much” for them, indicating that the intervention was not acceptable to these participants. Stroke is a serious life changing event and participation in a research study straight after discharge from hospital may not be the most appropriate time for stroke survivors. As detailed in section 8.8.2, changing the time of the intervention to approximately one month post stroke may promote retention of participants in the study. In addition having a percentage increase in step count each week may be daunting to some stroke survivors, and the success of using graduated addition approaches (such as those used by (Fitzsimons et al., 2008)) may be more appropriate to use with this patient group. Studies that have used a graduated addition approach, compared to percentage increase, had improved results at follow-

up meaning they are potentially more likely to provide sustained behaviour change (Fitzsimons et al., 2008, McMurdo et al., 2010).

Recruitment problems also forced changes to the original design of the programme of work. The original plan had been to carry out an uncontrolled pilot study of the behaviour change intervention followed by a controlled trial. Both of these studies would test the feasibility and acceptability of the behaviour change intervention.

Along with feasibility and acceptability, it was initially planned that the preliminary effects of the intervention would be evaluated. However, due to low recruitment in the initial pilot study (study five) it was not possible to conduct a randomised controlled study as the feasibility and acceptability of the intervention had not been fully assessed. The necessity of a second uncontrolled pilot study (study six) rendered conducting a controlled pilot study impossible due to the time constraints within the PhD programme.

9.4. Physical activity after stroke- where are we now?

The cycle of low physical activity and low physical fitness after stroke has long been established, for which physical fitness training has been recommended [Saunders et al 2013]. However, the benefits of fitness training are often lost to follow-up and many stroke survivors do not meet recommended physical activity guidelines [Field et al 2013]. Since beginning this PhD statements from the American Heart Association/ American Stroke Association have highlighted that physical activity and exercise prescription should be incorporated into the management of stroke survivors (Billinger et al., 2014). A recent systematic review of the long term participation in physical activity by stroke survivors included 11 studies of 1704 stroke survivors.

(Morris et al., 2014). Two intervention types were identified: individualised tailored counselling with or without supervised exercise (n=6 studies) and supervised exercise with advice (n=5 studies). Three studies illustrated increased odds of meeting recommended PA levels and participation in PA at 12 months after tailored counselling ($P<.05$). Two studies showed improved step count at three months with supervised exercise only ($P<.05$); however, PA levels had declined by three months (Morris et al., 2014). Tailored home exercise was the only predominantly exercise-based intervention to demonstrate higher PA participation at 12 months (Morris et al., 2014).

This programme of work has demonstrated that increasing physical activity after stroke can be complex. It has highlighted the key components of behaviour change that should be included in physical activity interventions after stroke. Further, it has used these key components to develop a carefully-structured and theoretically-driven behaviour change intervention. However, the behaviour change intervention was difficult to implement with stroke survivors and the reasons behind this remain unclear. To determine if the intervention does increase physical activity after stroke, further research is required. An exploratory randomised controlled trial would need to be undertaken to determine if the intervention does increase physical activity, however work is first needed to the intervention to ensure a suitable sample of participants would take part in an exploratory trial.

9.5. Where now for the behaviour change intervention?

The aim of designing a behaviour change intervention to increase physical activity after stroke settings was achieved. The six studies included in this PhD thesis have

contributed to the identification of the key behaviour change components of the intervention. These studies have also shown how these behaviour change components could be incorporated into a structured intervention. The aim of fully evaluating the behaviour change intervention after stroke was only partially achieved. The stroke survivors who completed the intervention found it both feasible and acceptable, however these numbers were small due to high drop-out rates and lower than expected recruitment. There was no single reason why participants dropped out of the behaviour change intervention. As discussed earlier in the previous chapter, a possible way to combat high drop-out rates may be to target the intervention at a later stage in the recovery after stroke process. This may give each stroke survivor time to settle back at home after their stroke, before beginning the intervention. This may give participants time to sort any personal or social difficulties arising from their stroke.

To successfully implement this behaviour change intervention with stroke survivors changes are likely needed to be made to the intervention, which in its current form did not yield the anticipated results. The essential next steps of the behaviour change intervention are detailed in the following section.

9.6. Directions for future research

Key areas identified as potential areas of future research are:

1. *Further investigations to validate the ability of different pedometers and accelerometers to detect the step counts of stroke survivors:*

Difficulty in measuring physical activity after stroke has proven to be a challenge during this PhD. The three possible ways to monitor activity trialled during the behaviour change intervention included pedometry (OMRON-HJ-113E), accelerometry (activPAL™) and self-report (estimates of minutes walking). Although the preferred measurement of physical activity in this PhD (due to the immediate feedback) the accuracy of the OMRON-HJ-113E pedometer played a vital role in the development of the behaviour change intervention and determined which stroke survivors were able to take part in the intervention. The inaccuracies of the OMRON-HJ-113E pedometer led to the inclusion of the second group of participants, who only recorded the minutes they spent waking each day. This is a very subjective measure of physical activity, which proved to be difficult for participants to conduct accurately. Although the most accurate at measuring physical activity, the activPAL™ still undercounts steps of stroke survivors (Sugavanam, 2014). Recently attempts have been made to validate the Actical accelerometer for use with stroke survivors (Serra et al., 2017). The Actical accelerometer is another brand of accelerometer similar to that of the activPAL™ that attempts to determine the wearers energy expenditure and step count (Kayes et al., 2009, Serra et al., 2017). However, this study also found that the Actical accelerometer was not suitable for stroke survivors due to undercounting steps (Serra et al., 2017). Finding and validating a suitable device for the behaviour change intervention that provides feedback to the wearer, may be integral in the success of the behaviour change intervention.

Therefore a study to validate differing models of pedometers and accelerometers would be beneficial for future trialling of the intervention. This would allow us to determine the most accurate device for detecting step counts in the majority of stroke survivors.

2. Perceptions and experiences of stroke survivors, who have previously taken part in exercise referral schemes or physical activity research studies, should be explored to determine what encouraged maintenance within these programmes:

Attrition was very high in the behaviour change intervention, and the reasons behind this remain unclear. The Edinburgh Leisure Exercise after Stroke is a successful physical activity programme run within the city, which includes a group exercise programmes specifically targeted to stroke survivors. The Edinburgh Leisure programme is very well attended by stroke survivors in Edinburgh, however is not often accessible to all stroke survivors. Determining what were the key components that encouraged attendance at the Edinburgh Leisure classes could potentially be beneficial in understanding why our behaviour change intervention was not well received.

3. Exploring the views of stroke survivors on sitting time after stroke, and incorporating these views into the behaviour change intervention to tackle increased sitting time and reduced physical activity after stroke:

Reducing sedentary behaviour after stroke is a new and developing research area that goes hand in hand with increasing physical activity after stroke. Sedentary behaviour is any waking behaviour characterised by an energy expenditure ≤ 1.5 metabolic equivalents, while sitting, reclining or lying posture (Tremblay et al., 2017). Research suggests that even if people are physically active after stroke, they can still be sedentary for long periods of time throughout the day (Wullems et al., 2016). There is increasing evidence that stroke survivors are highly sedentary and recent American Heart Association/ American Stroke Association guidelines encourage the reduction of sedentary time after stroke (Tieges et al., 2015, Young et al., 2016, Billinger et al., 2014). Stroke survivors have been identified as more sedentary (20.4 ± 2.7 h versus 17.5 ± 3.8 h, $p < 0.001$) and take fewer daily steps (4035 ± 2830 steps/day versus 8394 ± 2941 steps/day, $p < 0.001$) than age-matched healthy controls (Paul et al., 2016). A longitudinal cohort study of acute stroke survivors, who were followed for one year after stroke (Tieges et al., 2015). These stroke survivors spent, on average, 81% of each 24-hour period sedentary and are typically more sedentary in the afternoon and evening (Tieges et al., 2015). Importantly, the pattern of sedentary behaviour did not change over the first year following stroke and was independent of functional ability (Tieges et al., 2015). Recent international guidelines encourage the reduction of sedentary time after stroke, but how to do this remains unclear (Young et al., 2016). Therefore, it may be necessary to consider the implications of high sedentary behaviour on increasing physical

activity after stroke and how this would influence the behaviour change intervention.

4. *An exploratory trial of the behaviour change intervention to evaluate the effectiveness of the intervention:*

Once any planned changes are made to the behaviour change intervention, the definitive step would be to determine if the intervention can increase physical activity. This would be done as a randomised controlled trial comparing two groups of comparable stroke survivors. One group would receive the behaviour change intervention and while the other group would receive normal care and their physical activity would be measured at 6 and 12 months post stroke. Power calculations would be undertaken to determine the numbers of participants required to take part in the study.

9.7. Conclusion

The overall aim of this programme of work was to design and evaluate an evidence-based, theoretically-driven behaviour change intervention to increase physical activity, predominantly through walking, after stroke. In order to address this, six interlinked studies were undertaken in accordance with the MRC framework for developing and evaluating complex interventions. The development of behaviour change interventions can often be a long drawn out process with constant need for evaluation of feasibility of the intervention to the target population. As detailed in the MRC framework for developing and evaluating complex interventions, the process of developing interventions is often cyclical with the need for re-evaluation of ideas.

The field of increasing physical activity after stroke is still incomplete. Further carefully designed trials are required and these should evaluate long-term delivery of interventions and determine long-term outcome. It is clear that stroke is a complex and challenging condition and each stroke survivor presents their own set of unique problems and concerns when discharged from hospital. There is increasing awareness in the need to improve physical activity after stroke, and provisions for increasing physical activity in the community are on the rise. However stroke survivors choose to increase their physical activity, the benefits of physical activity socially, physically and mentally are evident.

In conclusion, this programme of works supports the notion that there is a need to find optimal ways to increase physical activity after stroke. Research highlights reduced physical activity can lead to secondary strokes, increased disability and reduced physical fitness. A theory-driven approach was undertaken to develop a sound behaviour change intervention, which was successfully implemented with a small group of stroke survivors. High drop-out rates suggest the intervention may need to be tailored to individuals. The start time of the intervention may also play an integral role in participants sticking to the intervention. Key areas for future research have been highlighted and taking these forward will ensure this behaviour change intervention can optimally increase the physical activity amongst stroke survivors.

REFERENCES

- ABRAHAM, C. & MICHIE, S. 2008. A taxonomy of behavior change techniques used in interventions. *Health Psychol*, 27, 379-87.
- ADAMS, H. P., JR., BENDIXEN, B. H., KAPPELLE, L. J., BILLER, J., LOVE, B. B., GORDON, D. L. & MARSH, E. E., 3RD 1993. Classification of subtype of acute ischemic stroke. Definitions for use in a multicenter clinical trial. TOAST. Trial of Org 10172 in Acute Stroke Treatment. *Stroke*, 24, 35-41.
- AMARENCO, P. & LABREUCHE, J. 2009. Lipid management in the prevention of stroke: review and updated meta-analysis of statins for stroke prevention. *Lancet Neurol*, 8, 453-63.
- ATS 2002. ATS statement: guidelines for the six-minute walk test. *Am J Respir Crit Care Med*, 166, 111-7.
- BANDURA, A. 1977. Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84, 191-215.
- BANDURA, A. 1989. Social Cognitive Theory. *Annals of child development*, 6, 1 - 60.
- BARLOW, J., WRIGHT, C., SHEASBY, J., TURNER, A. & HAINSWORTH, J. 2002. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns*, 48, 177-87.
- BAZZANO, L. A., GU, D., WHELTON, M. R., WU, X., CHEN, C. S., DUAN, X., CHEN, J., CHEN, J. C. & HE, J. 2010. Body mass index and risk of stroke among Chinese men and women. *Ann Neurol*, 67, 11-20.
- BECKER, M. H., HAEFNER, D. P., KASL, S. V., KIRSCHT, J. P., MAIMAN, L. A. & ROSENSTOCK, I. M. 1977. Selected psychosocial models and correlates of individual health-related behaviours. *Medical Care*, 15, 27-46.
- BILLINGER, S. A., ARENA, R., BERNHARDT, J., ENG, J. J., FRANKLIN, B. A., JOHNSON, C. M., MACKAY-LYONS, M., MACKO, R. F., MEAD, G. E., ROTH, E. J., SHAUGHNESSY, M. & TANG, A. 2014. Physical Activity and Exercise Recommendations for Stroke Survivors: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association. *Stroke*.
- BLAIR, S. N. 2009. Physical inactivity: the biggest public health problem of the 21st century. *Br J Sports Med*, 43, 1-2.
- BONETTI, D. & JOHNSTON, M. 2008. Perceived control predicting the recovery of individual-specific walking behaviours following stroke: testing psychological models and constructs. *Br J Health Psychol*, 13, 463-78.
- BOYSEN, G., KRARUP, L. H., ZENG, X., OSKEDRA, A., KORV, J., ANDERSEN, G., GLUUD, C., PEDERSEN, A., LINDAHL, M., HANSEN, L., WINKEL, P. & TRUELSEN, T. 2009. ExStroke Pilot Trial of the effect of repeated instructions to improve physical activity after ischaemic stroke: a multinational randomised controlled clinical trial. *Bmj*, 339, b2810.
- BRAZZELLI, M., SAUNDERS, D. H., GREIG, C. A. & MEAD, G. E. 2011. Physical fitness training for stroke patients. *Cochrane Database Syst Rev*, Cd003316.

- BRUG, J., CAMPBELL, M. & VAN ASSEMA, P. 1999. The application and impact of computer-generated personalized nutrition education: a review of the literature. *Patient Educ Couns*, 36.
- BRUNO-PETRINA. 2014. *Motor Recovery after Stroke* [Online]. <http://emedicine.medscape.com/article/324386-overview#aw2aab6b4> [Accessed 23/06 2016].
- BURNS, P. B., ROHRICH, R. J. & CHUNG, K. C. 2011. The Levels of Evidence and their role in Evidence-Based Medicine. *Plastic and reconstructive surgery*, 128, 305-310.
- BUSIJA, L., TAO, L. W., LIEW, D., WEIR, L., YAN, B., SILVER, G., DAVIS, S. & HAND, P. J. 2013. Do patients who take part in stroke research differ from non-participants? Implications for generalizability of results. *Cerebrovascular Diseases*, 35, 483-491.
- CAMPBELL BURTON, C., MURRAY, J., HOLMES, J., ASTIN, F., GREENWOOD, D. & KNAPP, P. 2013. Frequency of anxiety after stroke: a systematic review and meta-analysis of observational studies. *International Journal of Stroke*, 8, 545-559.
- CAMPBELL, M., FITZPATRICK, R., HAINES, A., KINMONTH, A. L., SANDERCOCK, P., SPIEGELHALTER, D. & TYRER, P. 2000. Framework for design and evaluation of complex interventions to improve health. *British Medical Journal*, 321, 694-696.
- CANE, J., O'CONNOR, D. & MICHIE, S. 2012. Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implement Sci*, 7, 37.
- CARROLL, S. L., GREIG, C. A., LEWIS, S. J., MCMURDO, M. E., SNIEHOTTA, F. F., JOHNSTON, M., JOHNSTON, D. W., SCOPES, J. & MEAD, G. E. 2012. The use of pedometers in stroke survivors: are they feasible and how well do they detect steps? *Arch Phys Med Rehabil*, 93, 466-70.
- CASPERSEN, C. J., POWELL, K. E. & CHRISTENSON, G. M. 1985. Physical activity, exercise and physical fitness: Definitions and distinctions for health-related research. *Public Health Reports*, 100, 126-131.
- CASTILLA-GUERRA, L. & FERNANDEZ-MORENO MDEL, C. 2012. Update on the management of hypertension for secondary stroke prevention. *Eur Neurol*, 68, 1-7.
- CHERRY. 2014. *What is a Theory?* [Online]. <http://psychology.about.com/od/tindex/f/theory.htm>. [Accessed 09/03 2015].
- COUPAR, F., POLLOCK, A., ROWE, P., WEIR, C. & LANGHORNE, P. 2012. Predictors of upper limb recovery after stroke: a systematic review and meta-analysis. *Clin Rehabil*, 26, 291-313.
- CRAIG, DIEPPE, P., MACINTYRE, S., MITCHIE, S., NAZARETH, I. & PETTICREW, M. 2008. Developing and evaluating complex interventions: the new Medical Research Council guidance. *British Medical Journal*, 337.
- CRAMER, S. C. 2008. Repairing the human brain after stroke: I. Mechanisms of spontaneous recovery. *Ann Neurol*, 63, 272-87.
- CUMMING, T. B., TYEDIN, K., CHURILOV, L., MORRIS, M. E. & BERNHARDT, J. 2012. The effect of physical activity on cognitive function after stroke: a systematic review. *Int Psychogeriatr*, 24, 557-67.

- DAMUSH, T. M., PLUE, L., BAKAS, T., SCHMID, A. & WILLIAMS, L. S. 2007. Barriers and facilitators to exercise among stroke survivors. *Rehabil Nurs*, 32, 253-60, 262.
- DAVIES, G., REILLY, J., MCGOWAN, A., DALL, P., GRANAT, M. & PATON, J. 2012. Validity, practical utility, and reliability of the activPAL in preschool children. *Medicine and science in sports and exercise*, 44, 761-768.
- DEPLANQUE, D., MASSE, I., LEFEBVRE, C., LIBERSA, C., LEYS, D. & BORDET, R. 2006. Prior TIA, lipid-lowering drug use, and physical activity decrease ischemic stroke severity. *Neurology*, 67, 1403-10.
- DEPLANQUE, D., MASSE, I., LIBERSA, C., LEYS, D. & BORDET, R. 2012. Previous leisure-time physical activity dose dependently decreases ischemic stroke severity. *Stroke Res Treat*, doi:10.1155/2012/614925.
- DHAMOON, M. S., SCIACCA, R. R., RUNDEK, T., SACCO, R. L. & ELKIND, M. S. 2006. Recurrent stroke and cardiac risks after first ischemic stroke: the Northern Manhattan Study. *Neurology*, 66, 641-6.
- DIEP, L., KWAGYAN, J., KURANTSIN-MILLS, J., WEIR, R. & JAYAM-TROUTH, A. 2010. Association of physical activity level and stroke outcomes in men and women: a meta-analysis. *J Womens Health (Larchmt)*, 19, 1815-22.
- DUNCAN, F., KUTLUBAEV, M. A., DENNIS, M. S., GREIG, C. & MEAD, G. E. 2012. Fatigue after stroke: a systematic review of associations with impaired physical fitness. *Int J Stroke*, 7, 157-62.
- EGAN, K. J., JANSSEN, H., SENA, E. S., LONGLEY, L., SPEARE, S., HOWELLS, D. W., SPRATT, N. J., MACLEOD, M. R., MEAD, G. E. & BERNHARDT, J. 2014. Exercise Reduces Infarct Volume and Facilitates Neurobehavioral Recovery Results From a Systematic Review and Meta-analysis of Exercise in Experimental Models of Focal Ischemia. *Neurorehabilitation and neural repair*, 28, 800-812.
- ELSWORTH, C., DAWES, H., WINWARD, C., HOWELLS, K., COLLETT, J., DENNIS, A., SACKLEY, C. & WADE, D. 2009. Pedometer step counts in individuals with neurological conditions. *Clin Rehabil*, 23, 171-5.
- ENG, J. J. & REIME, B. 2014. Exercise for depressive symptoms in stroke patients: a systematic review and meta-analysis. *Clin Rehabil*, 28, 731-739.
- ENGLISH, C., MANNS, P. J., TUCAK, C. & BERNHARDT, J. 2014. Physical Activity and Sedentary Behaviors in People With Stroke Living in the Community: A Systematic Review. *Physical Therapy*, 94, 185-196.
- FEIGIN, V. L., FOROUZANFAR, M. H., KRISHNAMURTHI, R., MENSAH, G. A., CONNOR, M., BENNETT, D. A., MORAN, A. E., SACCO, R. L., ANDERSON, L., TRUELSEN, T., O'DONNELL, M., VENKETASUBRAMANIAN, N., BARKER-COLLO, S., LAWES, C. M., WANG, W., SHINOHARA, Y., WITT, E., EZZATI, M., NAGHAVI, M. & MURRAY, C. 2014. Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet*, 383, 245-54.
- FEIGIN, V. L., LAWES, C. M., BENNETT, D. A., BARKER-COLLO, S. L. & PARAG, V. 2009. Worldwide stroke incidence and early case fatality reported in 56 population-based studies: a systematic review. *Lancet Neurol*, 8, 355-69.

- FIELD, M. J., GEBRUERS, N., SHANMUGA SUNDARAM, T., NICHOLSON, S. & MEAD, G. 2013. Physical activity after stroke: a systematic review and meta-analysis. *ISRN Stroke*, doi:10.1155/2013/464176.
- FISHBEIN, M., TRIANDIS, H. C., KANFER, F. H., BECKER, M. H., MIDDLESTADT, S. E. & EICHLER, A. 2001. Factors influencing behaviour and behaviour change *In*: BAUM, A., REVENSON, T. & SINGER, J. (eds.) *Handbook of health psychology* Hillsdale, NJ: Lawrence Erlbaum.
- FITZSIMONS, C., BAKER, G., GRAY, S., NIMMO, M., MUTRIE, N. & COLLABORATION, T. S. P. A. R. 2012. Does physical activity counselling enhance the effects of a pedometer-based intervention over the long-term: 12-month findings from the Walking for Wellbeing in the west study. *Bmc Public Health*, 12, 206.
- FITZSIMONS, C., BAKER, G., WRIGHT, A., NIMMO, M., WARD THOMPSON, C., LOWRY, R., MILLINGTON, C., SHAW, R., FENWICK, E., OGILVIE, D., INCHLEY, J., FOSTER, C. & MUTRIE, N. 2008. The 'Walking for Wellbeing in the West' randomised controlled trial of a pedometer-based walking programme in combination with physical activity consultation with 12 month follow-up: rationale and study design. *Bmc Public Health*, 8, 259.
- FRANCO, M. R., TONG, A., HOWARD, K., SHERRINGTON, C., FERREIRA, P. H., PINTO, R. Z. & FERREIRA, M. L. 2015. Older people's perspectives on participation in physical activity: a systematic review and thematic synthesis of qualitative literature. *Br J Sports Med*, 49, 1268-76.
- FURIE, K. L., KASNER, S. E., ADAMS, R. J., ALBERS, G. W., BUSH, R. L., FAGAN, S. C., HALPERIN, J. L., JOHNSTON, S. C., KATZAN, I., KERNAN, W. N., MITCHELL, P. H., OVBIAGELE, B., PALESCH, Y. Y., SACCO, R. L., SCHWAMM, L. H., WASSERTHEIL-SMOLLER, S., TURAN, T. N. & WENTWORTH, D. 2011. Guidelines for the prevention of stroke in patients with stroke or transient ischemic attack: a guideline for healthcare professionals from the american heart association/american stroke association. *Stroke*, 42, 227-76.
- GALLANAGH, S., QUINN, T. J., ALEXANDER, J. & WALTERS, M. R. 2011. Physical activity in the prevention and treatment of stroke. *ISRN neurology*, doi: 10.5402/2011/953818.
- GEBRUERS, N., VANROY, C., TRUIJEN, S., ENGELBORGHES, S. & DE DEYN, P. P. 2010. Monitoring of physical activity after stroke: a systematic review of accelerometry-based measures. *Arch Phys Med Rehabil*, 91, 288-97.
- GERTZ, K., PRILLER, J., KRONENBERG, G., FINK, K. B., WINTER, B., SCHROCK, H., JI, S., MILOSEVIC, M., HARMS, C., BOHM, M., DIRNAGL, U., LAUFS, U. & ENDRES, M. 2006. Physical activity improves long-term stroke outcome via endothelial nitric oxide synthase-dependent augmentation of neovascularization and cerebral blood flow. *Circ Res*, 99, 1132-40.
- GODFREY, A., CULHANE, K. & LYONS, G. 2007. Comparison of the performance of the activPAL™ Professional physical activity logger to a discrete accelerometer-based activity monitor. *Medical engineering & physics*, 29, 930-934.
- GOLDSTEIN, L. B., BUSHNELL, C. D., ADAMS, R. J., APPEL, L. J., BRAUN, L. T., CHATURVEDI, S., CREAGER, M. A., CULEBRAS, A., ECKEL, R. H.,

- HART, R. G., HINCHEY, J. A., HOWARD, V. J., JAUCH, E. C., LEVINE, S. R., MESCHIA, J. F., MOORE, W. S., NIXON, J. V. & PEARSON, T. A. 2011. Guidelines for the Primary Prevention of Stroke: A Guideline for Healthcare Professionals From the American Heart Association/American Stroke Association. *Stroke*, 42, 517-584.
- GOLICKI, D., NIEWADA, M., BUCZEK, J., KARLIŃSKA, A., KOBAYASHI, A., JANSSEN, M. F. & PICKARD, A. S. 2015a. Validity of EQ-5D-5L in stroke. *Quality of Life Research*, 24, 845-850.
- GOLICKI, D., NIEWADA, M., KARLIŃSKA, A., BUCZEK, J., KOBAYASHI, A., JANSSEN, M. F. & PICKARD, A. S. 2015b. Comparing responsiveness of the EQ-5D-5L, EQ-5D-3L and EQ VAS in stroke patients. *Qual Life Res*, 24, 1555-63.
- GOLLWITZER, P. M. & OETTINGEN, G. 1998. The emergence and implementation of health goals. *Psychology and Health*, 13, 687-715.
- GÓMEZ, J. F., CURCIO, C.-L., ALVARADO, B., ZUNZUNEGUI, M. V. & GURALNIK, J. 2013. Validity and reliability of the Short Physical Performance Battery (SPPB): a pilot study on mobility in the Colombian Andes. *Colombia Médica : CM*, 44, 165-171.
- GREEN, J. & YOUNG, J. 2001. A test-retest reliability study of the Barthel Index, the Rivermead Mobility Index, the Nottingham Extended Activities of Daily Living Scale and the Frenchay Activities Index in stroke patients. *Disability and rehabilitation*, 23, 670-676.
- GURALNIK, J. M., FERRUCCI, L., PIEPER, C. F., LEVEILLE, S. G., MARKIDES, K. S., OSTIR, G. V., STUDENSKI, S., BERKMAN, L. F. & WALLACE, R. B. 2000. Lower extremity function and subsequent disability consistency across studies, predictive models, and value of gait speed alone compared with the short physical performance battery. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 55, M221-M231.
- GURALNIK, J. M., SIMONSICK, E. M., FERRUCCI, L., GLYNN, R. J., BERKMAN, L. F., BLAZER, D. G., SCHERR, P. A. & WALLACE, R. B. 1994. A short physical performance battery assessing lower extremity function: association with self-reported disability and prediction of mortality and nursing home admission. *Journal of gerontology*, 49, M85-M94.
- HACKAM, D. G. & SPENCE, J. D. 2007. Combining multiple approaches for the secondary prevention of vascular events after stroke: a quantitative modeling study. *Stroke*, 38, 1881-5.
- HACKETT, M. L. & PICKLES, K. 2014. Part I: frequency of depression after stroke: an updated systematic review and meta-analysis of observational studies. *International Journal of Stroke*, 9, 1017-1025.
- HAMILTON, M., HAMILTON, D. & ZDERIC, T. 2007. Role of low energy expenditure and sitting in obesity, metabolic syndrome, type 2 diabetes, and cardiovascular disease. *Diabetes*, 56, 2655 - 2667.
- HAN, C.-W., YAJIMA, Y., LEE, E.-J., NAKAJIMA, K., MEGURO, M. & KOHZUKI, M. 2005. Validity and utility of the Craig Hospital Inventory of Environmental Factors for Korean community-dwelling elderly with or without stroke. *The Tohoku journal of experimental medicine*, 206, 41-49.

- HARRINGTON, D. M., WELK, G. J. & DONNELLY, A. E. 2011. Validation of MET estimates and step measurement using the ActivPAL physical activity logger. *Journal of sports sciences*, 29, 627-633.
- HENDRICKS, H. T., VAN LIMBEEK, J., GEURTS, A. C. & ZWARTS, M. J. 2002. Motor recovery after stroke: a systematic review of the literature. *Arch Phys Med Rehabil*, 83, 1629-37.
- HENSON, J., YATES, T., BIDDLE, S. J., EDWARDSON, C. L., KHUNTI, K., WILMOT, E. G., GRAY, L. J., GORELY, T., NIMMO, M. A. & DAVIES, M. J. 2013. Associations of objectively measured sedentary behaviour and physical activity with markers of cardiometabolic health. *Diabetologia*, 56, 1012-20.
- HUNGER, M., SABARIEGO, C., STOLLENWERK, B., CIEZA, A. & LEIDL, R. 2012. Validity, reliability and responsiveness of the EQ-5D in German stroke patients undergoing rehabilitation. *Qual Life Res*, 21, 1205-16.
- INVESTIGATORS, W. 1988. The World Health Organization MONICA Project (monitoring trends and determinants in cardiovascular disease): a major international collaboration. WHO MONICA Project Principal Investigators. *J Clin Epidemiol*, 41, 105-14.
- ISD. 2015. *Stroke statistics update* [Online]. <https://isdscotland.scot.nhs.uk/Health-Topics/Stroke/Publications/2015-01-27/2015-01-27-Stroke-Report.pdf?99271792174>. [Accessed 13/07/2015 2015].
- ISLAM, M. S., ANDERSON, C. S., HANKEY, G. J., HARDIE, K., CARTER, K., BROADHURST, R. & JAMROZIK, K. 2008. Trends in incidence and outcome of stroke in Perth, Western Australia during 1989 to 2001: the Perth Community Stroke Study. *Stroke*, 39, 776-82.
- JANSEN, I. & LEBLANC, A. G. 2010. Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. *Int J Behav Nutr Phys Act*, 7, 40.
- JELLEMA, S., VAN HEES, S., ZAJEC, J., VAN DER SANDE, R., NIJHUIS-VAN DER SANDEN, M. W. & STEULTJENS, E. M. 2016. What environmental factors influence resumption of valued activities post stroke: A systematic review of qualitative and quantitative findings. *Clinical Rehabilitation*, 0269215516671013.
- JOHNSTON, BONETTI, D., JOICE, S., POLLARD, B., MORRISON, V., FRANCIS, J. J. & MACWALTER, R. 2007. Recovery from disability after stroke as a target for a behavioural intervention: results of a randomized controlled trial. *Disabil Rehabil*, 29, 1117-27.
- JOHNSTON, M., MORRISON, V., MACWALTER, R. & PARTRIDGE, C. 1999. Perceived control, coping and recovery from disability following stroke. *Psychology and health*, 14, 181-192.
- JONES, MANDY, A. & PARTRIDGE, C. 2009. Changing self-efficacy in individuals following a first time stroke: preliminary study of a novel self-management intervention. *Clinical Rehabilitation*, 23, 522-533.
- JORGENSEN, H. S., NAKAYAMA, H., RAASCHOU, H. O. & OLSEN, T. S. 1999. Stroke. Neurologic and functional recovery the Copenhagen Stroke Study. *Phys Med Rehabil Clin N Am*, 10, 887-906.
- JORGENSEN, H. S., NAKAYAMA, H., RAASCHOU, H. O., VIVE-LARSEN, J., STOIER, M. & OLSEN, T. S. 1995. Outcome and time course of recovery in

- stroke. Part II: Time course of recovery. The Copenhagen Stroke Study. *Arch Phys Med Rehabil*, 76, 406-12.
- KAPLAN, R. M. 1990. Behavior as the central outcome in health care. *Am Psychol*, 45, 1211-20.
- KAYES, N. M., SCHLUTER, P. J., MCPHERSON, K. M., LEETE, M., MAWSTON, G. & TAYLOR, D. 2009. Exploring actical accelerometers as an objective measure of physical activity in people with multiple sclerosis. *Arch Phys Med Rehabil*, 90, 594-601.
- KERNAN, W. N., OVBIAGELE, B., BLACK, H. R., BRAVATA, D. M., CHIMOWITZ, M. I., EZEKOWITZ, M. D., FANG, M. C., FISHER, M., FURIE, K. L. & HECK, D. V. 2014. Guidelines for the prevention of stroke in patients with stroke and transient ischemic attack. *Stroke*, 45, 2160-2236.
- KISSELA, B. M., KHOURY, J. C., ALWELL, K., MOOMAW, C. J., WOO, D., ADEOYE, O., FLAHERTY, M. L., KHATRI, P., FERIOLI, S., DE LOS RIOS LA ROSA, F., BRODERICK, J. P. & KLEINDORFER, D. O. 2012. Age at stroke: temporal trends in stroke incidence in a large, biracial population. *Neurology*, 79, 1781-7.
- KRARUP, L. H., TRUELSEN, T., GLUUD, C., ANDERSEN, G., ZENG, X., KORV, J., OSKEDRA, A. & BOYSEN, G. 2008. Prestroke physical activity is associated with severity and long-term outcome from first-ever stroke. *Neurology*, 71, 1313-8.
- KREISEL, S. H., HENNERICI, M. G. & BAZNER, H. 2007. Pathophysiology of stroke rehabilitation: the natural course of clinical recovery, use-dependent plasticity and rehabilitative outcome. *Cerebrovasc Dis*, 23, 243-55.
- LANGHORNE, P., COUPAR, F. & POLLOCK, A. 2009. Motor recovery after stroke: a systematic review. *Lancet Neurol*, 8, 741-54.
- LAU, P. W., LAU, E. Y., WONG, D. P. & RANSDELL, L. 2011. A systematic review of information and communication technology-based interventions for promoting physical activity behavior change in children and adolescents. *Journal of medical Internet research*, 13, e48.
- LAWES, C. M., BENNETT, D. A., FEIGIN, V. L. & RODGERS, A. 2004. Blood pressure and stroke: an overview of published reviews. *Stroke*, 35, 1024.
- LEE, FOLSOM, A. R. & BLAIR, S. N. 2003. Physical activity and stroke risk: a meta-analysis. *Stroke*, 34, 2475-81.
- LEE, SHAFE & COWIE 2011a. UK stroke incidence, mortality and cardiovascular risk management 1999–2008: time-trend analysis from the General Practice Research Database. *BMJ Open*, 1.
- LEE, C. M., COLAGIURI, S., EZZATI, M. & WOODWARD, M. 2011b. The burden of cardiovascular disease associated with high body mass index in the Asia-Pacific region. *Obes Rev*, 12, e454-9.
- LOUREIRO, A. P. C., GUARITA-SOUZA, L. C., LERDAL, A. & LANGHAMMER, B. 2014. A Review of the Relationship Between Poststroke Fatigue and Physical Activity. *Topics in Geriatric Rehabilitation*, 30, 296-306.
- LU, Y., HAJIFATHALIAN, K., EZZATI, M., WOODWARD, M., RIMM, E. B. & DANAEL, G. 2014. Metabolic mediators of the effects of body-mass index, overweight, and obesity on coronary heart disease and stroke: a pooled

- analysis of 97 prospective cohorts with 1.8 million participants. *Lancet*, 383, 970-83.
- MACKO, R. F., BENVENUTI, F., DRENG, V. M., TAVIANI, A., NESI, B. & WEINRICH, M. 2008. Adaptive physical activity improves mobility function and quality of life in chronic hemiparesis. *Journal of rehabilitation research and development*, 45, 323.
- MACKO, R. F., HAEUBER, E., SHAUGHNESSY, M., COLEMAN, K. L., BOONE, D. A., SMITH, G. V. & SILVER, K. H. 2002. Microprocessor-based ambulatory activity monitoring in stroke patients. *Med Sci Sports Exerc*, 34, 394-9.
- MAHONEY, F. I. & BARTHEL, D. W. 1965. FUNCTIONAL EVALUATION: THE BARTHEL INDEX. *Md State Med J*, 14, 61-5.
- MAYRING, P. 2014. Qualitative content analysis: theoretical foundation, basic procedures and software solution. *Social Science Open Access Repository* <http://nbn-resolving.de/urn:nbn:de:0168-ssoar-395173>
- MCMURDO, M. E., SUGDEN, J., ARGO, I., BOYLE, P., JOHNSTON, D. W., SNIEHOTTA, F. F. & DONNAN, P. T. 2010. Do pedometers increase physical activity in sedentary older women? A randomized controlled trial. *J Am Geriatr Soc*, 58, 2099-106.
- MEAD, G., LYNCH, J., GREIG, C., YOUNG, A., LEWIS, S. & SHARPE, M. 2007a. Evaluation of fatigue scales in stroke patients. *Stroke*, 38, 2090-2095.
- MEAD, G. E., GREIG, C. A., CUNNINGHAM, I., LEWIS, S. J., DINAN, S., SAUNDERS, D. H., FITZSIMONS, C. & YOUNG, A. 2007b. Stroke: a randomized trial of exercise or relaxation. *J Am Geriatr Soc*, 55, 892-9.
- MEGHERBI, S. E., MILAN, C., MINIER, D., COUVREUR, G., OSSEBY, G. V., TILLING, K., DI CARLO, A., INZITARI, D., WOLFE, C. D., MOREAU, T. & GIROUD, M. 2003. Association between diabetes and stroke subtype on survival and functional outcome 3 months after stroke: data from the European BIOMED Stroke Project. *Stroke*, 34, 688-94.
- MICHIE, ATKINS, L. & WEST, R. 2014. *The Behaviour Change Wheel: a guide to designing interventions*, Silverback Publishing.
- MICHIE, JOHNSTON, M., ABRAHAM, C., LAWTON, R., PARKER, D. & WALKER, A. 2005. Making psychological theory useful for implementing evidence based practice: a consensus approach. *Quality and safety in health care*, 14, 26-33.
- MICHIE, JOHNSTON, M., FRANCIS, J., HARDEMAN, W. & ECCLES, M. 2008. From theory to intervention: mapping theoretically derived behavioural determinants to behaviour change techniques. *Applied psychology*, 57, 660-680.
- MICHIE, S., VAN STRALEN, M. & WEST, R. 2011. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6, 42.
- MOL, V. J. & BAKER, C. A. 1991. Activity intolerance in the geriatric stroke patient. *Rehabilitation Nursing*, 16, 337-343.
- MORRIS, J., OLIVER, T., KROLL, T. & MACGILLIVRAY, S. 2012. The importance of psychological and social factors in influencing the uptake and maintenance of physical activity after stroke. *Stroke Research and Treatment*, doi:10.1155/2012/195249.

- MORRIS, J. H., MACGILLIVRAY, S. & MCFARLANE, S. 2014. Interventions to promote long-term participation in physical activity after stroke: a systematic review of the literature. *Arch Phys Med Rehabil*, 95, 956-67.
- MORRIS, J. H., OLIVER, T., KROLL, T., JOICE, S. & WILLIAMS, B. 2015. From physical and functional to continuity with pre-stroke self and participation in valued activities: A qualitative exploration of stroke survivors', carers' and physiotherapists' perceptions of physical activity after stroke. *Disability and rehabilitation*, 37, 64-77.
- MORRIS, J. H., OLIVER, T., KROLL, T., JOICE, S. & WILLIAMS, B. 2016. Physical activity participation in community dwelling stroke survivors: synergy and dissonance between motivation and capability. A qualitative study. *Physiotherapy*, 10.1016/j.physio.2016.05.001.
- MOZAFFARIAN, D., BENJAMIN, E. J., GO, A. S., ARNETT, D. K., BLAHA, M. J., CUSHMAN, M., DE FERRANTI, S., DESPRES, J. P., FULLERTON, H. J., HOWARD, V. J., HUFFMAN, M. D., JUDD, S. E., KISSELA, B. M., LACKLAND, D. T., LICHTMAN, J. H., LISABETH, L. D., LIU, S., MACKEY, R. H., MATCHAR, D. B., MCGUIRE, D. K., MOHLER, E. R., 3RD, MOY, C. S., MUNTNER, P., MUSSOLINO, M. E., NASIR, K., NEUMAR, R. W., NICHOL, G., PALANIAPPAN, L., PANDEY, D. K., REEVES, M. J., RODRIGUEZ, C. J., SORLIE, P. D., STEIN, J., TOWFIGHI, A., TURAN, T. N., VIRANI, S. S., WILLEY, J. Z., WOO, D., YEH, R. W. & TURNER, M. B. 2015. Heart disease and stroke statistics--2015 update: a report from the American Heart Association. *Circulation*, 131, e29-322.
- MRC 2000. A framework for the development and evaluation of RCTs for complex interventions to improve health. In: MRC (ed.). <https://www.mrc.ac.uk/documents/pdf/rcts-for-complex-interventions-to-improve-health/>.
- MUKHERJEE, D. & PATIL, C. G. 2011. Epidemiology and the global burden of stroke. *World Neurosurg*, 76, S85-90.
- MUTRIE, N., BLAMEY, A. & DAVIDSON, R. 1993 Class based and home based activities for older people. . In: RESEARCH DIGEST NO 30 (ed.) *research report no 32*. Edinburgh: Scottish Sports Council.
- NASREDDINE, Z. S., PHILLIPS, N. A., BEDIRIAN, V., CHARBONNEAU, S., WHITEHEAD, V., COLLIN, I., CUMMINGS, J. L. & CHERTKOW, H. 2005. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc*, 53, 695-9.
- NEWCASTLE CULTURE LAB. 2013. *Newcastle Culture Lab* [Online]. <http://www.ncl.ac.uk/culturelab/>. [Accessed 22/02 2015].
- NHSSCOTLAND 2009. Better heart disease and stroke care action plan. In: SCOTTISH GOVERNMENT (ed.). <https://www.chss.org.uk/documents/2014/10/better-heart-disease-and-stroke-care-action-plan-2009-pdf.pdf>.
- NICE. 2007. *Behaviour change: general approaches* [Online]. <https://www.nice.org.uk/guidance/ph6/resources/behaviour-change-general-approaches-55457515717>: National Institute for Healthcare and Excellence. [Accessed November 2016].

- NICE. 2014. *Behaviour Change: individual approaches* [Online]. <https://www.nice.org.uk/guidance/ph49>: National Institute for Health and Care Excellence [Accessed November 2016].
- NICHOLSON, S., SNIEHOTTA, F. F., VAN WIJCK, F., GREIG, C. A., JOHNSTON, M., MCMURDO, M. E. T., DENNIS, M. & MEAD, G. E. 2013. A systematic review of perceived barriers and motivators to physical activity after stroke. *International Journal of Stroke*, 8, 357-364.
- NICHOLSON, S. L., GREIG, C. A., SNIEHOTTA, F., JOHNSTON, M., LEWIS, S. J., MCMURDO, M. E. T., JOHNSTON, D., SCOPES, J. & MEAD, G. E. 2017. Quantitative data analysis of perceived barriers and motivators to physical activity in stroke survivors *J R Coll Physicians Edinb*, 47, 231-236.
- NICHOLSON, DONAGHY, M., JOHNSTON, M., SNIEHOTTA, F. F., VAN WIJCK, F., JOHNSTON, D., GREIG, C., MCMURDO, M. E. & MEAD, G. 2014. A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity. *Disabil Rehabil*, 36, 1857-68.
- NOCON, M., HIEMANN, T., MULLER-RIEMENSCHNEIDER, F., THALAU, F., ROLL, S. & WILLICH, S. N. 2008. Association of physical activity with all-cause and cardiovascular mortality: a systematic review and meta-analysis. *Eur J Cardiovasc Prev Rehabil*, 15, 239-46.
- NOURI, F. & LINCOLN, N. 1987. An extended activities of daily living scale for stroke patients. *Clinical rehabilitation*, 1, 301-305.
- OLIVER, M., BADLAND, H. M., SHEPHERD, J. & SCHOFIELD, G. M. 2011. Counting steps in research: a comparison of accelerometry and pedometry. *Open Journal of Preventive Medicine*, 1, 1.
- ORROW, KINMONTH, A.-L., SANDERSON, S. & SUTTON, S. 2012. Effectiveness of physical activity promotion based in primary care: systematic review and meta-analysis of randomised controlled trials. *BMJ*, 344, e1389.
- OUTERMANS, J., POOL, J., PORT, I., BAKERS, J. & WITTINK, H. 2016. What's keeping people after stroke from walking outdoors to become physically active? A qualitative study, using an integrated biomedical and behavioral theory of functioning and disability. *BMC neurology*, 16, 137.
- PALTECHNOLOGIES. 2010. *PAL technologies: providing the evidence* [Online]. <http://www.paltechnologies.com/products/>: PAL. [Accessed February 2017].
- PATTERSON, S. & ROSS-EDWARDS, B. 2009. Long-term stroke survivors' needs and perceptions of an exercise maintenance model of care. *International Journal of Therapy & Rehabilitation*, 16.
- PAUL, L., BREWSTER, S., WYKE, S., GILL, J. M., ALEXANDER, G., DYBUS, A. & RAFFERTY, D. 2016. Physical activity profiles and sedentary behaviour in people following stroke: a cross-sectional study. *Disabil Rehabil*, 38, 362-7.
- PAYNE, A., GREIG, C., YOUNG, A. & MEAD, G. 2001. Views of stroke patients on physical fitness training. *Age Ageing*, 30, 429.
- PETERS, S. A., HUXLEY, R. R. & WOODWARD, M. 2013. Smoking as a risk factor for stroke in women compared with men: a systematic review and meta-analysis of 81 cohorts, including 3,980,359 individuals and 42,401 strokes. *Stroke*, 44, 2821-8.

- PETERS, S. A. E., HUXLEY, R. R. & WOODWARD, M. 2014. Diabetes as a risk factor for stroke in women compared with men: a systematic review and meta-analysis of 64 cohorts, including 775 385 individuals and 12 539 strokes. *The Lancet*, 383, 1973-1980.
- PIN-BARRE, C. & LAURIN, J. 2015. Physical Exercise as a Diagnostic, Rehabilitation, and Preventive Tool: Influence on Neuroplasticity and Motor Recovery after Stroke. *Neural Plasticity*, 2015, 608581.
- PROPER, K. I., BEEK, A. J. V. A. N. D. E. R., HILDEBRANDT, V. H., TWISK, J. W. & VAN MECHELEN, W. 2003. Short term effect of feedback on fitness and health measurements on self reported appraisal of the stage of change. *Br J Sports Med*, 37.
- RAND, D., ENG, J. J., TANG, P.-F., JENG, J.-S. & HUNG, C. 2009. How Active Are People With Stroke?: Use of Accelerometers to Assess Physical Activity. *Stroke*, 40, 163-168.
- REIMERS, C. D., KNAPP, G. & REIMERS, A. K. 2009. Exercise as stroke prophylaxis. *Dtsch Arztebl Int*, 106, 715-721.
- REINER, M., NIERMANN, C., JEKAUC, D. & WOLL, A. 2013. Long-term health benefits of physical activity—a systematic review of longitudinal studies. *BMC public health*, 13, 813.
- RESNICK, B., MICHAEL, K., SHAUGHNESSY, M., KOPUNEK, S., SHIM NAHM, E. & MACKO, R. F. 2008. Motivators for treadmill exercise after stroke. *Topics in stroke rehabilitation*, 15, 494-502.
- RIMMER, WANG, E. & SMITH, D. 2008. Barriers associated with exercise and community access for individuals with stroke. *J Rehabil Res Dev*, 45, 315-22.
- RIMMER, J. H., RAUWORTH, A. E., WANG, E. C., NICOLA, T. L. & HILL, B. 2009. A preliminary study to examine the effects of aerobic and therapeutic (nonaerobic) exercise on cardiorespiratory fitness and coronary risk reduction in stroke survivors. *Archives of physical medicine and rehabilitation*, 90, 407-412.
- ROBISON, J., WILES, R., ELLIS-HILL, C., MCPHERSON, K., HYNDMAN, D. & ASHBURN, A. 2009. Resuming previously valued activities post-stroke: who or what helps? *Disability and rehabilitation*, 31, 1555-1566.
- ROTHWELL, P. M., COULL, A. J., GILES, M. F., HOWARD, S. C., SILVER, L. E., BULL, L. M., GUTNIKOV, S. A., EDWARDS, P., MANT, D., SACKLEY, C. M., FARMER, A., SANDERCOCK, P. A., DENNIS, M. S., WARLOW, C. P., BAMFORD, J. M. & ANSLOW, P. 2004. Change in stroke incidence, mortality, case-fatality, severity, and risk factors in Oxfordshire, UK from 1981 to 2004 (Oxford Vascular Study). *Lancet*, 363, 1925-33.
- RUDD, T. 2009. *Stroke* [Online].
http://www.bgs.org.uk/index.php?option=com_content&view=article&id=378:stroke&catid=12:goodpractice&Itemid=106 . : British Geriatric Society.
 [Accessed July 2012].
- RUTHERFORD. 2012. *Population ageing: statistics* [Online].
<http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN03228>.
 [Accessed September 2016].

- RYAN, C. G., GRANT, P. M., TIGBE, W. W. & GRANAT, M. H. 2006. The validity and reliability of a novel activity monitor as a measure of walking. *British Journal of Sports Medicine*, 40, 779 - 784.
- SACCO, R. L., GAN, R., BODEN-ALBALA, B., LIN, I. F., KARGMAN, D. E., HAUSER, W. A., SHEA, S. & PAIK, M. C. 1998. Leisure-time physical activity and ischemic stroke risk: the Northern Manhattan Stroke Study. *Stroke*, 29, 380-7.
- SAGEN, U., VIK, T. G., MOUM, T., MORLAND, T., FINSET, A. & DAMMEN, T. 2009. Screening for anxiety and depression after stroke: comparison of the hospital anxiety and depression scale and the Montgomery and Asberg depression rating scale. *J Psychosom Res*, 67, 325-32.
- SAKA, Ö., MCGUIRE, A. & WOLFE, C. 2009. Cost of stroke in the United Kingdom. *Age and Ageing*, 38, 27-32.
- SALLIS, R. 2011. Developing healthcare systems to support exercise: exercise as the fifth vital sign. *Br J Sports Med*, 45, 473-4.
- SARKER, S. J., RUDD, A. G., DOUIRI, A. & WOLFE, C. D. 2012. Comparison of 2 extended activities of daily living scales with the Barthel Index and predictors of their outcomes: cohort study within the South London Stroke Register (SLSR). *Stroke*, 43, 1362-9.
- SAUNDERS, D. H., SANDERSON, M., BRAZZELLI, M., GREIG, C. & MEAD, G. 2013. Physical fitness training for stroke patients. *The Cochrane database of systematic reviews*, 10.
- SAWYER & ARONI, R. A. 2005. Self-management in adolescents with chronic illness. What does it mean and how can it be achieved? *Medical Journal of Australia*, 183, 405.
- SCANDINAVIAN STROKE STUDY GROUP 1985. Multicenter trial of hemodilution in ischemic stroke--background and study protocol. Scandinavian Stroke Study Group. *Stroke*, 16, 885-90.
- SCHNEIDER, P. L., CROUTER, S. E., LUKAJIC, O. & BASSETT, D. R., JR. 2003. Accuracy and reliability of 10 pedometers for measuring steps over a 400-m walk. *Med Sci Sports Exerc*, 35, 1779-84.
- SCOBIE, L., WYKE, S. & DIXON, D. 2009. Identifying and applying psychological theory to setting and achieving rehabilitation goals. *Clin Rehabil*, 23, 321-33.
- SERRA, M. C., BALRAJ, E., DISANZO, B. L., IVEY, F. M., HAFER-MACKO, C. E., TREUTH, M. S. & RYAN, A. S. 2017. Validating accelerometry as a measure of physical activity and energy expenditure in chronic stroke. *Topics in stroke rehabilitation*, 24, 18-23.
- SHAUGHNESSY, M., RESNICK, B. M. & MACKO, R. F. 2006. Testing a model of post-stroke exercise behavior. *Rehabil Nurs*, 31, 15-21.
- SIGN 2010. Management of patients with stroke: Rehabilitation, prevention and management of complications, and discharge planning. In: NETWORK, S. I. G. (ed.).
- SIGNAL, N., MCPHERSON, K., LEWIS, G., KAYES, N., SAYWELL, N., MUDGE, S. & TAYLOR, D. 2016. What influences acceptability and engagement with a high intensity exercise programme for people with stroke? A qualitative descriptive study. *NeuroRehabilitation*, 1-11.

- SIPAHI, I., SWAMINATHAN, A., NATESAN, V., DEBANNE, S. M., SIMON, D. I. & FANG, J. C. 2012. Effect of antihypertensive therapy on incident stroke in cohorts with prehypertensive blood pressure levels: a meta-analysis of randomized controlled trials. *Stroke*, 43, 432-40.
- SMITH, SAUNDERS, D. H. & MEAD, G. 2012. Cardiorespiratory fitness after stroke: a systematic review. *Int J Stroke*, 7, 499-510.
- SNIEHOTTA, F. F., SCHOLZ, U. & SCHWARZER, R. 2005. Bridging the intention-behaviour gap: Planning, self-efficacy, and action control in the adoption and maintenance of physical exercise. *Psychology & Health*, 20, 143-160.
- STRAZZULLO, P., D'ELIA, L., CAIRELLA, G., GARBAGNATI, F., CAPPuccio, F. P. & SCALFI, L. 2010. Excess body weight and incidence of stroke: meta-analysis of prospective studies with 2 million participants. *Stroke*, 41, e418-26.
- STROUD, N., MAZWI, T. M., CASE, L. D., BROWN, R. D., JR., BROTT, T. G., WORRALL, B. B. & MESCHIA, J. F. 2009. Prestroke physical activity and early functional status after stroke. *J Neurol Neurosurg Psychiatry*, 80, 1019-22.
- STUART, M., BENVENUTI, F., MACKO, R., TAVIANI, A., SEGENNI, L., MAYER, F., SORKIN, J. D., STANHOPE, S. J., MACELLARI, V. & WEINRICH, M. 2009. Community-based adaptive physical activity program for chronic stroke: feasibility, safety, and efficacy of the Empoli model. *Neurorehabilitation and neural repair*.
- SUGAVANAM, T., MEAD, G., BULLEY, C., DONAGHY, M. & VAN WIJCK, F. 2013. The effects and experiences of goal setting in stroke rehabilitation - a systematic review. *Disabil Rehabil*, 35, 177-90.
- SUGAVANAM, T. P. 2014. *Person-centred goal setting for exercise after stroke*. PhD, Queen Margaret University.
- SYME, P. D., BYRNE, A. W., CHEN, R., DEVENNY, R. & FORBES, J. F. 2005. Community-based stroke incidence in a Scottish population: the Scottish Borders Stroke Study. *Stroke*, 36, 1837-43.
- THE SCOTTISH GOVERNMENT 2009. People and Culture in Scotland 2008: Results from the Scottish Household Survey Culture and Sport Module 2007/2008. <http://www.gov.scot/Publications/2009/11/24085939/38>
- THE STROKE ASSOCIATION. 2017. *State of the Nation: stroke statistics* [Online]. <https://www.stroke.org.uk/resources/state-nation-stroke-statistics>. [Accessed 26/02/2017 2017].
- THOM, T., HAASE, N., ROSAMOND, W., HOWARD, V. J., RUMSFELD, J., MANOLIO, T., ZHENG, Z.-J., FLEGAL, K., O'DONNELL, C. & KITTNER, S. 2006. Heart disease and stroke statistics—2006 update a report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation*, 113, e85-e151.
- TIEGES, Z., MEAD, G., ALLERHAND, M., DUNCAN, F., VAN WIJCK, F., FITZSIMONS, C., GREIG, C. & CHASTIN, S. 2015. Sedentary Behavior in the First Year After Stroke: A Longitudinal Cohort Study With Objective Measures. *Archives of Physical Medicine and Rehabilitation*, 96, 15-23.
- TREMBLAY, M. S., AUBERT, S., BARNES, J. D., SAUNDERS, T. J., CARSON, V., LATIMER-CHEUNG, A. E., CHASTIN, S. F. M., ALTENBURG, T. M.

- & CHINAPAW, M. J. M. 2017. Sedentary Behavior Research Network (SBRN) - Terminology Consensus Project process and outcome. *Int J Behav Nutr Phys Act*, 14, 75.
- TYSON, S. F., HANLEY, M., CHILLALA, J., SELLEY, A. & TALLIS, R. C. 2006. Balance disability after stroke. *Physical therapy*, 86, 30.
- VANROY, C., VANLANDEWIJCK, Y., CRAS, P., FEYS, H., TRUIJEN, S., MICHELSEN, M. & VISSERS, D. 2014. Is a coded physical activity diary valid for assessing physical activity level and energy expenditure in stroke patients? *PloS one*, 9, e98735.
- WADE, D. T. 2009. Goal setting in rehabilitation: an overview of what, why and how. *Clin Rehabil*, 23, 291-5.
- WANG, X., DONG, Y., QI, X., HUANG, C. & HOU, L. 2013. Cholesterol levels and risk of hemorrhagic stroke: a systematic review and meta-analysis. *Stroke*, 44, 1833-9.
- WARBURTON, D. E. R., NICOL, C. W. & BREDIN, S. S. D. 2006. Health benefits of physical activity: the evidence. *Canadian Medical Association Journal*, 174, 801-809.
- WARMS, C. 2006. Physical activity measurement in persons with chronic and disabling conditions: methods, strategies, and issues. *Fam Community Health*, 29, 78s-88s.
- WATKINSON, C., VAN SLUIJS, E. M., SUTTON, S., MARTEAU, T. & GRIFFIN, S. J. 2010. Randomised controlled trial of the effects of physical activity feedback on awareness and behaviour in UK adults: the FAB study protocol [ISRCTN92551397]. *BMC Public Health*, 10, 1-10.
- WENDEL-VOS, G. C., SCHUIT, A. J., FESKENS, E. J., BOSHUIZEN, H. C., VERSCHUREN, W. M., SARIS, W. H. & KROMHOUT, D. 2004. Physical activity and stroke. A meta-analysis of observational data. *Int J Epidemiol*, 33, 787-98.
- WEST, T. & BERNHARDT, J. 2011. Physical activity in hospitalised stroke patients. *Stroke Research and Treatment*, 2012.
- WHO 2010. WHO Guidelines Approved by the Guidelines Review Committee. *Global Recommendations on Physical Activity for Health*. Geneva: World Health Organization
- Copyright (c) World Health Organization 2010.
- WHO. 2012. *Prevalence of insufficient physical activity* [Online]. WHO. [Accessed 31/03/2016].
- WOOD, A. M., WHITE, I. R. & THOMPSON, S. G. 2004. Are missing outcome data adequately handled? A review of published randomized controlled trials in major medical journals. *Clinical trials*, 1, 368-376.
- WULLEMS, J. A., VERSCHUREN, S. M., DEGENS, H., MORSE, C. I. & ONAMBELE, G. L. 2016. A review of the assessment and prevalence of sedentarism in older adults, its physiology/health impact and non-exercise mobility counter-measures. *Biogerontology*, 17, 547-65.
- YATSUYA, H., TOYOSHIMA, H., YAMAGISHI, K., TAMAKOSHI, K., TAGURI, M., HARADA, A., OHASHI, Y., KITA, Y., NAITO, Y., YAMADA, M., TANABE, N., ISO, H. & UESHIMA, H. 2010. Body mass index and risk of stroke and myocardial infarction in a relatively lean

- population: meta-analysis of 16 Japanese cohorts using individual data. *Circ Cardiovasc Qual Outcomes*, 3, 498-505.
- YOUNG, D. R., HIVERT, M. F., ALHASSAN, S., CAMHI, S. M., FERGUSON, J. F., KATZMARZYK, P. T., LEWIS, C. E., OWEN, N., PERRY, C. K., SIDDIQUE, J. & YONG, C. M. 2016. Sedentary Behavior and Cardiovascular Morbidity and Mortality: A Science Advisory From the American Heart Association. *Circulation*, 134, e262-79.
- ZHAO, N. 2010. Full-featured pedometer design realized with 3-Axis digital accelerometer. *Analog Dialogue*, 44.
- ZIGMOND, A. & SNAITH, R. 1983. The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.

APPENDICES

APPENDIX 1: MEDLINE search strategy for systematic review

MEDLINE: 15/07/2010

STROKE search strategy:

1. Exp cerebrovascular disorders/
2. (stroke\$ or poststroke or post-stroke or cva\$ or cerebrovasc\$ or cerebral
vasc\$ or apoplexy\$).tw
3. ((brain\$ or cerebr\$ or cerebell\$ or vertebrobasilar or cortical or hemispher\$
or intracran\$ or intracerebral or MCA or anterior circu\$ or posterior circu\$ or
basal ganglia) adj5 (ish?emi\$ or infarct\$ or thrombo\$ or emboli\$ or apoplexy
or occlus\$ or obstruction or vasculopathy)).tw
4. ((brain\$ or cerebr\$ or cerebell\$ or subarachnoid or parenchymal or intracran\$
or intracerebral or basal ganglia or subdural) adj5 (haemorrhage\$ or
hemorrhage\$ or haematoma\$ or hemetoma\$ or bleed\$)).tw
5. brain injuries/ or brain injury, chronic/
6. ataxia/ or anomia/ or exp aphasia/ or dysarthria/ or hemiplegia/ or exp
paresis/ or deglutition disorders/ or hemianopsia
7. (hemipleg\$ or hemipar\$ or paresis\$ or paretic or hemianop\$ or spasticity or
inattention or aphasi\$ or apraxi\$ or dysphasi\$ or dysphagi\$ or deglutition
disorder\$ or swallow\$ disorder\$ or dysarthri\$).tw
8. ((unilateral or visual or hemispatial or attentional or spatial) adj5 neglect).tw
9. or/1-8

PHYSICAL ACTIVITY search strategy:

10. exp exercise/ or exercise test/ or exercise tolerance/
11. physical exertion/
12. physical fitness/
13. exp physical endurance
14. physical therapy modalities/ or dance therapy/ or tai ji/ or yoga/ or exp
exercise therapy/
15. exp locomotion/
16. early ambulation/
17. exp sports/
18. leisure activities/ or recreation/ or sports/
19. isometric contraction/ or isotonic contraction/
20. (physical adj3 (exercise\$ or therap\$ or conditioning or activit\$ or fitness)).tw
21. (exercise adj3 (train\$ or intervention\$ or protocol\$ or program\$ or therap\$ or
activit\$ or regime\$)).tw
22. (fitness adj3 (train\$ or intervention\$ or protocol\$ or program\$ or therap\$ or
activit\$ or regim\$)).tw
23. ((training or conditioning) adj3 (intervention\$ or protocol\$ or program\$ or
activit\$ or regim\$)).tw

24. (sport\$ or recreation\$ or leisure or cycl\$ or bicycl\$ or treadmill\$ or run\$ or swim\$ or walk\$).tw
25. ((endurance or aerobic or cardio\$) adj3 (fitness or train\$ or intervention\$ or protocol\$ or program\$ or therap\$ or activit\$ or regime\$)).tw
26. (muscle strengthening or progressive resist\$).tw
27. ((weight or strength\$ or resistance) adj (train\$ or lift\$ or exercise\$)).tw
28. ((isometric or isotonic or eccentric or concentric) adj (contraction\$ or exercise\$)).tw
29. or/10-28

BARRIERS AND MOTIVATORS search strategy:

30. motivation/ or "aspirations (psychology)"/ or "conflict (psychology)"/ or goals/ or intention/
31. exp attitude to health/ or health behavior/
32. self efficacy/
33. health knowledge, attitudes, practice/
34. health services accessibility/
35. exp social environment
36. exp health promotion
37. (barrier\$ or difficult\$ or obstacle\$ or prevent\$).tw
38. (motivate\$ or facilita\$ or enable\$ or promote or encourage\$).tw
39. or 30-38
40. 9 and 29 and 39

APPENDIX 2: Ethical approval for qualitative study

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ



TM/LBH/app-mrecamend

28/09/2010

Dr Gillian E Mead
Senior Lecturer in Geriatric Medicine, Room F1642
Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh
EH16 4SA

RESEARCH &
DEVELOPMENT
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343
Email:
R&DOffice@luht.scot.nhs.uk

Director:
Professor David E Newby

Dear Dr Gillian E Mead

REC No: 09/S1101/38
R&D Project ID No: 2009/W/ME/03
Title of Research *Using pedometers to promote physical activity in patients after stroke: a pilot study*

I am writing in reply to recent correspondence in relation to the following amendment(s) to the above project.

- Amendment:** No 2, dated 17th August 2010
- Participants will be approached once they have been discharged from hospital for more than 5 months, to ask if they are willing to undertake a qualitative interview.
 - Protocol, version 2, dated 17th August 2010
 - Patient Information Sheet, version 4, dated 17th August 2010
 - Consent form, version 3, dated 17th August 2010

We have now received a copy of the amendment(s) and assessed any consequential changes in NHS Lothian resource use. I confirm that NHS Lothian management approval is extended to cover the specific changes intimated. You should be aware that approval for this amendment should be sought from REC before it is implemented

Yours sincerely

A handwritten signature in black ink, appearing to read 'Tina McLelland'.

Dr Tina McLelland
R&D Governance Manager
Direct Tel: 0131-242-3340
Email tina.mclelland@nhs.net

"Improving health through excellence and innovation in clinical research"

APPENDIX 3: Participant information sheet and consent form for qualitative study

Patient information sheet. Version 4. 17th August 2010



1. Study Title

Using pedometers to promote physical activity in patients after stroke: a pilot study

2. Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank for reading this.

3. What is the purpose of this study?

Physical activity is generally recommended to people who have had a stroke, but some people aren't certain how best to increase their activity. One possible way to help people increase activity is to use a pedometer, a small wrist-watch like device which records step counts, along with advice on how to increase step counts. For people who have had a stroke, one potential problem is that pedometers may not be able to accurately record step counts, and some people who have had a stroke may find it difficult to put on a pedometer, take it off and read the pedometer screen.

We want to find out how easy it is for people who have had a stroke to use a pedometer, and also how accurately pedometers measure step counts. We also want to find out what people after stroke think about physical activity.

We also wish to determine the barriers and motivators people who have had a stroke feel towards physical activity. We wish to understand stroke patients' views about pedometers and how best to encourage their use in trials to promote physical activity.

4. Why have I been chosen to take part?

You have been chosen to take part because you have recently had a stroke. This study will recruit 50 patients who have had a stroke from stroke wards and stroke clinics in Edinburgh and Livingstone over a 6 month period.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you receive.

6. What will happen to me if I take part?

The researcher will visit you on the ward shortly before you are due to go home. We will gather information from your medical notes about the type of stroke you've had and how it's affected you. We may also speak to the team looking after you to get more information about your stroke. We will record whether you need to use a stick or a frame for walking.

Next, we will ask you some questions about how much exercise you took before your stroke. We will also ask you to answer two short questions about what you think about walking. Half the participants will answer the questions both before and after using the pedometer, and half will be asked to complete the questions only afterwards.

We will then ask you put on three pedometers. A pedometer is a small device, which looks a bit like a wrist watch. We will ask you to put on the pedometer in three positions: around the neck, attached to a waist belt above the leg which has been affected by your stroke, and attached to a waist belt above the leg which has not been affected by your stroke. We will ask you how easy you find it to put on and take off the pedometer.

We will then ask you to do two walking tests on the wards. First, we will ask you to sit down for 10 seconds, stand up for 10 seconds, walk for 20 seconds, and then sit down. We will then ask you to walk at your own pace for 6 minutes. We will record the distance you can cover in 6 minutes so that we can calculate your walking speed. At the end of the walks, we will ask you to read the step count displayed on the pedometer screen. We will video-record the two walks so that one of the research team can look at the videos and compare the number steps recorded by the video with the pedometer recording.

We will ask you whether you would consider using a pedometer as a part of future studies to increase physical activity using a 4 point rating scale e.g. yes definitely, yes probably, probably not, definitely not. We will also ask you

about your views about physical activity and discuss how much activity you did prior to your stroke.

We will also invite you to take home the pedometer, and use it at home for 1 week. At the end of the week, we will telephone you and ask you to read out how many steps the pedometer has recorded, and we will then ask you to return the pedometer in the post.

We will contact you again after you have been discharged from hospital (around 6-10 months). We will ask if you are willing to undergo a short interview (which we will audio record), which will take place at your home at a time convenient to you by our research assistant Sarah Carroll. This will determine the barriers and motivators you have felt towards physical activity since your discharge.

7. What do I have to do?

There are no lifestyle restrictions.

8. What are the possible benefits of taking part?

Some patients find it helpful to talk to someone about their symptoms after a stroke. The information we get from the study may help us to better treat patients with stroke in the future.

9. What are the possible disadvantages and risks of taking part?

Apart from the possible inconvenience of the researcher taking up some of your time, we do not envisage any particular risks to your taking part. The walking test may make you feel a little puffed out.

10. What happens when the research study stops?

We will analyse the data and publish it in a journal. It will not be possible to identify you from the publication.

For further information, please see Part 2 of this information sheet.

11. What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

12. Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

13. Contact Details:

For further information, please contact Dr Gillian Mead, Senior Lecturer in Geriatric Medicine, who is leading the study. Her phone number is 0131 242 6481.

If you have any concerns about the study, please contact Dr Mead in the first instance.

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

14. What if relevant new information becomes available?

If new information relevant to this project becomes available during the course of study, we will let you know about this.

15. What will happen if I don't want to carry on with the study?

If you decide during the walking tests that you do not want to complete the study, you can withdraw from the study. However, if you do decide to withdraw, we would like to keep any data which we have already collected.

16. What if there is a problem?

If you have a complaint about your treatment by members of staff (doctors, nurses etc) you should complain through the usual NHS complaints system.

If you have a complaint about the research you are involved in, you should complain to Dr Mead in the first instance. If there is a reportable serious adverse event, Dr Mead will report this to the sponsor of the study (NHS Lothian and University of Edinburgh).

17. Complaints:

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (0131 242 6481). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

18. Harm:

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against (NHS Lothian or University of Edinburgh) but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

The University of Edinburgh has insurance. You may be able to make a claim.

19. Will my taking part in this study be kept confidential?

Our procedures for handling, processing, storage and destruction of their data are compliant with the Data Protection Act 1998.

We will obtain your permission to access your medical records and to collect data about you during the course of the study.

Information about you will be collected onto paper forms. These will be stored securely in a locked filing cabinet, in a locked office at the Royal Infirmary hospital. Dr Mead will be in charge of the data. The research team will be authorized to have access to the data. The sponsors of the research (University of Edinburgh and NHS Lothian), regulatory authorities will have access, as necessary, to view the data for monitoring the quality of research. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site. Data which identifies you as an individual will be destroyed 12 months after the end of the study.

After we have collected data from each visit, the data will be entered onto a computer data base, held at the University of Edinburgh. When this is done, you will be given a unique code number, so that you cannot be identified by the information stored on the computer data base.

The video recordings will be stored on a secure, password protected site on the University of Edinburgh server.

You have the right to check the accuracy of data held about them and correct any errors.

20. Involvement of the General Practitioner/Family doctor (GP)

Your own general practitioner will be informed about your participation in the study. If you are still in hospital when we do the study, we will write in your medical records that you are taking part.

21. What will happen to any samples I give?

We will not be taking any samples. We will store the video recordings for 6 months after the end of the study.

22. Will any genetic tests be done?

No

23. What will happen to the results of the research study?

The results of the study will be published in medical journals. We will also send a report to the Chief Scientist Office of the Scottish Government (which is funding the study). If you would like to see the results, please ask and we can make sure that you are sent a copy. You will not be identified in any report or publication. It will not be possible to identify you from this publication.

24. Who is organising and funding the research?

The Chief Scientist Office of the Scottish Government is funding the research. The University of Edinburgh and NHS Lothian are co-sponsors of the research and are overseeing it. Dr Mead who is the Principal Investigator is in charge of the running of the study. She is not being paid for including you in the study.

25. Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS (or private sector) by the Lothian Research Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for considering taking part.

Study Number:
Patient Identification Number for this study

GERIATRIC MEDICINE
Clinical and Surgical Sciences

SCHOOL of CLINICAL
SCIENCES
and COMMUNITY HEALTH

The University of Edinburgh
Room S1642
Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh EH16 4SA

CONSENT FORM
Version 3 17.08.10

**Title of Project: Using pedometers to promote
physical activity in patients after stroke: a pilot study**

Name of Researcher: Dr Gillian Mead

Please initial box

1. I confirm that I have read and understand the information sheet dated August 2010 version 4 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from University of Edinburgh, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree to my GP being informed of my participation in the study. ☐

5. **I agree to be contacted on one further occasion after my discharge to discuss my views on physical activity. These views will be audio recorded.** ☐

6. I agree to take part in the above study. ☐

Name of Patient Date Signature

Name of Person taking consent Date Signature
(if different from researcher)

Researcher Date Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

APPENDIX 4: Ethical approval for the validation study

South East Scotland Research Ethics Committee 01

Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG

Tel: 0131 465 5679

11 January 2012

Dr Gillian Mead
Senior Lecturer in Geriatric Medicine
Room F1642, Royal Infirmary
Little France Crescent
Edinburgh
EH16 4SA

Dear Dr Mead

Study title: Using pedometers to promote physical activity in patients after stroke: a pilot study
REC reference: 09/S1101/38
Amendment number: 3
Amendment date: 07 December 2011

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Consent Form	Version 4	07 December 2011
Participant Information Sheet	Version 5	07 December 2011
Protocol	Version 3	07 December 2011
Notice of Substantial Amendment (non-CTIMPs)		07 December 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/S1101/38:	Please quote this number on all correspondence
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Yours sincerely



Dr Janet Andrews
Chair

APPENDIX 5: Participant information sheet and consent form for validation study

Patient information sheet. Version 5. 7th December 2011

1. Study Title

Using accelerometers to promote physical activity in patients after stroke: a pilot study

2. Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank for reading this.

3. What is the purpose of this study?

Physical activity is generally recommended to people who have had a stroke, but some people aren't certain how best to increase their activity. One possible way to help people increase activity is to use an accelerometer, a small wrist-watch like device which records step counts, along with advice on how to increase step counts. For people who have had a stroke, one potential problem is that accelerometers may not be able to accurately record step counts, and some people who have had a stroke may find it difficult to put on an accelerometer, take it off and read the accelerometer screen.

We want to find out how easy it is for people who have had a stroke to use an accelerometer, and also how accurately accelerometers measure step counts.

4. Why have I been chosen to take part?

You have been chosen to take part because you have recently had a stroke. This study will recruit 20 patients who have had a stroke from stroke wards and stroke clinics in Edinburgh and Livingstone.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you receive.

6. What will happen to me if I take part?

The researcher will visit you on the ward shortly before you are due to go home. We will gather information from your medical notes about the type of stroke you've had and how it's affected you. We may also speak to the team looking after you to get more information about your stroke. We will record whether you need to use a stick or a frame for walking.

Next, we will ask you some questions about how much exercise you took before your stroke. We will also ask you to answer two short questions about what you think about walking. Half the participants will answer the questions both before and after using the accelerometer, and half will be asked to complete the questions only afterwards.

We will then ask you put on three accelerometers. An accelerometer is a small device, which looks a bit like a wrist watch. We will ask you to put on the accelerometer in three positions: around your wrist, attached to a waist belt above the leg which has been affected by your stroke, and attached to a waist belt above the leg which has not been affected by your stroke. We will ask you how easy you find it to put on and take off the accelerometer.

We will then ask you to do two walking tests on the wards. First, we will ask you to sit down for 10 seconds, stand up for 10 seconds, walk for 20 seconds, and then sit down. We will then ask you to walk at your own pace for 6 minutes. We will record the distance you can cover in 6 minutes so that we can calculate your walking speed. At the end of the walk, we will ask you to read the step count displayed on the accelerometer screen. We will video-record the two walks so that one of the research team can look at the videos and compare the number steps recorded by the video with the accelerometer recording.

We will ask you whether you would consider using an accelerometer as a part of future studies to increase physical activity using a 4 point rating scale e.g. yes definitely, yes probably, probably not, definitely not. We will also ask you about your views about physical activity and discuss how much activity you did prior to your stroke.

7. What do I have to do?

There are no lifestyle restrictions.

8. What are the possible benefits of taking part?

Some patients find it helpful to talk to someone about their symptoms after a stroke. The information we get from the study may help us to better treat patients with stroke in the future.

9. What are the possible disadvantages and risks of taking part?

Apart from the possible inconvenience of the researcher taking up some of your time, we do not envisage any particular risks to your taking part. The walking test may make you feel a little puffed out.

10. What happens when the research study stops?

We will analyse the data and publish it in a journal. It will not be possible to identify you from the publication.

For further information, please see Part 2 of this information sheet.

11. What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

12. Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

13. Contact Details:

For further information, please contact Dr Gillian Mead, Senior Lecturer in Geriatric Medicine, who is leading the study. Her phone number is 0131 242 6481.

If you have any concerns about the study, please contact Dr Mead in the first instance.

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

14. What if relevant new information becomes available?

If new information relevant to this project becomes available during the course of study, we will let you know about this.

15. What will happen if I don't want to carry on with the study?

If you decide during the walking tests that you do not want to complete the study, you can withdraw from the study. However, if you do decide to withdraw, we would like to keep any data which we have already collected.

16. What if there is a problem?

If you have a complaint about your treatment by members of staff (doctors, nurses etc) you should complain through the usual NHS complaints system.

If you have a complaint about the research you are involved in, you should complain to Dr Mead in the first instance. If there is a reportable serious adverse event, Dr Mead will report this to the sponsor of the study (NHS Lothian and University of Edinburgh).

17. Complaints:

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (0131 242 6481). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

18. Harm:

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against (NHS Lothian or University of Edinburgh) but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

The University of Edinburgh has insurance. You may be able to make a claim.

19. Will my taking part in this study be kept confidential?

Our procedures for handling, processing, storage and destruction of their data are compliant with the Data Protection Act 1998.

We will obtain your permission to access your medical records and to collect data about you during the course of the study.

Information about you will be collected onto paper forms. These will be stored securely in a locked filing cabinet, in a locked office at the Royal Infirmary hospital. Dr Mead will be in charge of the data. The research team will be authorized to have access to the data. The sponsors of the research (University of Edinburgh and NHS Lothian), regulatory authorities will have access, as necessary, to view the data for monitoring the quality of research. All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site. Data which identifies you as an individual will be destroyed 12 months after the end of the study.

After we have collected data from each visit, the data will be entered onto a computer data base, held at the University of Edinburgh. When this is done, you will be given a unique code number, so that you cannot be identified by the information stored on the computer data base.

The video recordings will be stored on a secure, password protected site on the University of Edinburgh server.

You have the right to check the accuracy of data held about them and correct any errors.

20. Involvement of the General Practitioner/Family doctor (GP)

Your own general practitioner will be informed about your participation in the study. If you are still in hospital when we do the study, we will write in your medical records that you are taking part.

21. What will happen to any samples I give?

We will not be taking any samples. We will store the video recordings for 6 months after the end of the study.

22. Will any genetic tests be done?

No

23. What will happen to the results of the research study?

The results of the study will be published in medical journals. We will also send a report to the Chief Scientist Office of the Scottish Government (which is funding the study). If you would like to see the results, please ask and we can make sure that you are sent a copy. You will not be identified in any

report or publication. It will not be possible to identify you from this publication.

24. Who is organising and funding the research?

The Chief Scientist Office of the Scottish Government is funding the research. The University of Edinburgh and NHS Lothian are co-sponsors of the research and are overseeing it. Dr Mead who is the Principal Investigator is in charge of the running of the study. She is not being paid for including you in the study.

25. Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS (or private sector) by the Lothian Research Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for considering taking part.



Study Number:
Patient Identification Number for this study

GERIATRIC MEDICINE
Clinical and Surgical Sciences

SCHOOL of CLINICAL
SCIENCES
and COMMUNITY HEALTH

The University of Edinburgh
Room S1642
Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh EH16 4SA

Secretaries: Mrs M Harding

CONSENT FORM
Version 4 07.12.11

Title of Project: Using **accelerometers** to promote physical activity in patients after stroke: a pilot study

Name of Researcher: Dr Gillian Mead

1. I confirm that I have read and understand the information sheet dated December 2011 version 5 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from University of Edinburgh, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I agree to my GP being informed of my participation in the study. ☐
5. I agree to take part in the above study. ☐

_____ Name of Patient	_____ Date	_____ Signature
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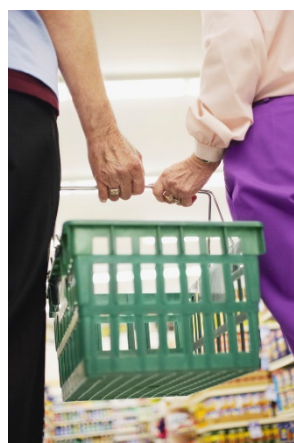
_____ Name of Person taking consent (if different from researcher)	_____ Date	_____ Signature
--	---------------	--------------------

_____ Researcher	_____ Date	_____ Signature
---------------------	---------------	--------------------

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

Increasing walking after stroke

Participant booklet



The research team would like to thank The Stroke
Association for funding this research



Contents

The aim of this booklet is to help you increase your walking. You and the researcher will work through this booklet together and plan how to increase your walking.

Section 1

Why walking is important

Section 2

Support from family and friends

Section 3

Family Information Sheet

Section 4

Action planning and coping planning

Section 5

Step counter instructions and Step Diary

Section 6

Study feedback (complete at the end of the study)

Section 1

This section gives you information about the benefits of increasing your walking after stroke. This section also covers any difficulties you might face as you try to increase your walking.

Why walking is important

Stroke survivors are often advised to do more physical activity. Walking is one of the easiest ways to do this. You can enjoy walking alone or with someone else. You can walk when you want, where you want and without much planning or special equipment.

Increasing walking may

- boost your energy levels
- lower your blood pressure and cholesterol, which may reduce the risk of a further stroke
- control your body weight
- prevent walking becoming difficult
- increase your fitness
- strengthen your bones

However you may find that increased walking may

- make you tired, especially if you begin doing too much, too soon
- cause muscle stiffness and aching. This tends to be temporary and is less likely to occur as your body becomes used to doing more walking

The researcher will have checked with your medical team that it is safe for you to take part in this study (There can be small risks involved when increasing walking, including falls and the risk of a heart attack). When you walk, please follow the advice from your own doctor/physiotherapist e.g. if you walk with an aid (e.g. Zimmer frame) please continue to do so whilst taking part in this study. If you begin to feel unwell when walking, please seek advice from your own doctor.

Importantly, in the longer term, we know that walking is good for your health and may reduce the risk of stroke and heart attack.

Section 2

This section is about how your family and friends can help you increase your walking. For each question circle the appropriate answer/s and write any comments.

Support from family and friends

How would your family and friends feel if you increased your walking?

Happy	Comments
Sad	
Calm	
Worried	
Supportive	
Unsupportive	

Would your family and friends support you increasing your walking?

Yes definitely	<i>Comments</i>
Yes probably	
Probably not	
Definitely not	
Unsure	

Would your family and friends increase their own walking with you?

Yes definitely	Comments
Yes probably	
Probably not	
Definitely not	
Unsure	

Would your family and friends go walking with you?

Yes definitely	Comments
Yes probably	
Probably not	
Definitely not	
Unsure	

Section 3

The following section contains an information sheet for your family and friends. It can be removed from the booklet and given to your friends and family members. If you need additional copies of the information sheet, let the researcher know.

Family Information Sheet

Stroke survivors are often advised to do more physical activity. Walking is one of the easiest ways to do this. Walking is one of the easiest ways to improve health and fitness.

Increasing walking may

- boost energy levels
- lower blood pressure and cholesterol, which may reduce the risk of a further stroke
- control body weight

- prevent walking becoming difficult
- increase fitness
- strengthen bones

..... has decided to participate in a 3 month study. The study aims to increase walking.

We will give a step counter. The step counter is a small device that records the number of steps walked and feeds this back to the user. The step counter is worn on a belt over the hip.

..... will be given weekly step targets. The researcher and will plan how to meet these step targets.

We will provide with motivation and support throughout the study to help boost his/her confidence.

How you can support

Sometimes it can be difficult to increase walking. If you encourage to walk, this may help him/her to continue to increase their walking.

If you try to increase your own walking, this could also help motivate and increase his/her confidence to take part in physical activity. If you walk with

this may also help you feel less anxious about their safety when they are out and about.

If you have any questions please contact **Sarah Nicholson** on **0131 242 6940**.

Section 4

This section will help you plan how to increase your walking. It will also help you to think about any difficulties you may face. In this section, you will record how confident you feel about increasing your walking.

Action planning and coping planning

Believing you are capable of increasing your walking is important. You may find planning how and when you will increase your walking helpful. Think about the challenges you may encounter when trying to carry out what you plan. This will help you to deal with difficulties if they arise.

Action plans and coping plans will be filled in with the help of the researcher. You do not need to fill in all 5 goals at the start of the study. As you progress through the study you may wish to add more goals or change your existing goals.

Below is an example goal.

What? Describe what you will do to achieve your goal	When? Describe the time of day and duration	How? Specify the situation	Potential problems that could happen?	How can I tackle these problems?
<i>1. Walk to the end of the street and back</i> <i>2. Walk to post box and back</i> <i>3. Walk to shops and back</i>	<i>First thing in morning after breakfast.</i>	<i>Ask husband to walk with me</i>	<i>1. Too tired to go out walking</i> <i>2. Husband can't walk with me.</i>	<i>1. Rest, but try and walk tomorrow</i> <i>2. Ask friend if they can walk with me.</i>

Goal 1				
What?	When?	How?	Potential problems?	How can I tackle potential problems?

Goal 2				
What?	When?	How?	Potential problems?	How can I tackle potential problems?

Goal 3				
What?	When?	How?	Potential problems?	How can I tackle potential problems?

Goal 4				
What?	When?	How?	Potential problems?	How can I tackle potential problems?

Your feelings

We know want to look at how confident you feel about walking. Having confidence in your own walking is important. Believing you are capable of increasing your walking can help you to achieve your walking goals.

To determine you confidence in increasing your walking during the study, please circle the appropriate answers for the following sentences.

I intend to increase my walking over the study period?

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

I am confident I will be able to increase my walking over the study period?

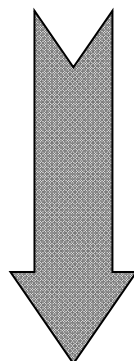
1 Least Confident

2

3

4

5 Most confident



To help achieve your goals you may need help from family or friends to take you out and walk with you, or take you to places where you can walk. Here are some suggestions that might help with this:

- encourage a family member(s) to go walking with you
- try to share driving amongst different family members and friends
- ask your stroke nurse about any local community stroke classes you could attend that offer transport
- enquire about volunteer driver services (e.g. WRVS Edinburgh Community Transport Service)

Many stroke survivors prefer walking outside. However, if you can't walk outside, walking around your house or garden may also help you achieve your step targets.

Section 5

In this section, please record the number of steps you walk each day. This will allow you to see the progress you make during the study. If you did not meet your step target, please make notes on each diary entry which might explain the reasons (i.e. feeling unwell, poor weather). These notes will help the research team understand the difficulties stroke survivors face when trying to increase their own walking. If you wish, family members or friend can help you read the step counter and fill out your step diary.

Step Diary

This step diary will allow you to track the progress of your walking and see the improvements you have made.

1. Each morning, as soon as you get up, put on the step counter
2. Leave it on all day
3. At bedtime remove the step counter
4. Record the number of steps from the step counter into your step diary

If you miss a day do not worry, but try not to forget the next day.

Step diary repeated for weeks 2- 7

Looking back

You are now half way through the 3 month study. Hopefully, you have already achieved some of your goals and the number of steps you walk each week has increased. If this is not the case, do not worry. There are still 6 weeks left of the study, when you can try and increase your walking.

Take a moment to look back at the barriers you felt at the beginning of the study. Have you managed to overcome any of these? Have any of these barriers changed since the start of the study?

Has your intention to increasing your walking altered since the beginning of the study? Circle the appropriate answer below

I intend to increase my walking over the rest of the study period?

Strongly agree

Agree

Neither agree nor disagree

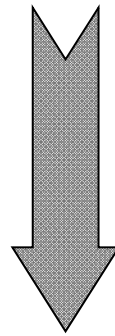
Disagree

Strongly disagree

Has your confidence to increasing your walking altered since the beginning of the study? Circle the appropriate answer below.

I am confident I will be able to increase my walking over the rest of the study period?

- 1 Least Confident
- 2
- 3
- 4
- 5 Most confident



Continue to look back through this booklet to remind yourself of what you have achieved. Some days may be more difficult than others. Continue to monitor your walking for the remaining 6 weeks. This will help you maintain your walking in the future.

Step dairy repeated for weeks 8-13

Date	Step count	Notes
Total weekly step count:		
Target weekly step count:		

Congratulations, you have now reached the end of the study.

The researcher should have already contacted you to arrange another visit. This visit should happen within the next week. This purpose of this

visit will be to collect the step counter and to repeat the 4 questionnaires and leg function test.

Section 6

Study feedback

Now that you have completed the 3 month study, please take a couple of minutes to fill out this feedback form. The information we receive will help us improve future studies for stroke survivors.

Do you think this study was

Too long?

Too short?

Just the right length?

How easy did you find reading the step counter?

Very easy

Quite easy

Neither easy nor difficult

Quite difficult

Very difficult

How easy did you find putting on the step counter?

Very easy

Quite easy

Neither easy nor difficult

Quite difficult

Very difficult

How easy was booklet to follow?

Very easy

Quite easy

Neither easy nor difficult

Quite difficult

Very difficult

Were the telephone calls from the researcher

Too frequent?

Not frequent enough?

About right?

Were you satisfied with the help and advice the intervention gave you?

1 2 3 4 5 6 7 8 9
10

(totally unsatisfied)

(totally satisfied)

Additional comments to the research team about the study

A large, empty rectangular box with a thin black border, intended for additional comments to the research team about the study.

APPENDIX 7: Ethical approval for intervention recruitment (round one)

Lothian NHS Board

South East Scotland Research Ethics Committee 01



Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000
Fax 0131 465 5789

www.nhslothian.scot.nhs.uk

Date 13 June 2012
Your Ref
Our Ref

Mrs Sarah L Nicholson
Stroke Association Junior Research Fellow
University of Edinburgh
Room S1642 Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh
EH16 4SA

Enquiries to: Sandra Wyllie
Extension: 35679
Direct Line: 0131 465 5679
Email: Sandra.Wyllie@nhslothian.scot.nhs.uk

Dear Mrs Nicholson

Study title: Testing a behavioural change intervention to increase walking after stroke
REC reference: 12/SS/0089

Thank you for your letter of 13 June 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.



INVESTORS
IN PEOPLE



Healthy
Working
Lives

Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Dr Charles J Winstanley
Interim Chief Executive Tim Davison
Lothian NHS Board is the common name of Lothian Health Board

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Response to Request for Further Information		13 June 2012
REC application		23 May 2012
Protocol	Version 2	13 June 2012
Participant Information Sheet	Version 2	13 June 2012
Participant Consent Form	Version 2	13 June 2012
Participant booklet	Version 2	13 June 2012
GP/Consultant Information Sheets	Version 1	22 May 2012
CV - Dr GE Mead		
CV - S Nicholson		
CV - CA Greig		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/SS/0089

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Janet Andrews
Chair

Email: Sandra.Wyllie@nhsllothian.scot.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

“After ethical review – guidance for researchers”

*Copy to: Marianne Laird
Karen Maitland, NHS Lothian*

APPENDIX 8: Ethical approval for intervention recruitment (round two)

Lothian NHS Board

South East Scotland Research Ethics Committee 01



Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000
Fax 0131 465 5789

www.nhslothian.scot.nhs.uk

Date 23 December 2013
Your Ref
Our Ref

Enquiries to: Sandra Wyllie
Extension: 35473
Direct Line: 0131 465 5473
Email: Sandra.Wyllie@nhslothian.scot.nhs.uk

Mrs Sarah L Nicholson
Stroke Association Junior Research Fellow
University of Edinburgh
Room S1642 Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh
EH16 4SA

Dear Mrs Nicholson

Study title: Testing a behavioural change intervention to increase walking after stroke
REC reference: 12/SS/0089
Amendment number: 01
Amendment date: 16 December 2013
IRAS project ID: 83570

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Pedometer participant booklet	Version 3	26 November 2013
Notice of Substantial Amendment (non-CTIMPs)		16 December 2013
Protocol	Version 3	09 December 2013
Participant Information Sheet	Version 3	09 December 2013
Participant Consent Form	Version 3	09 December 2013
Diary participant booklet	Version 3	26 November 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.



Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Mr Brian Houston
Chief Executive Tim Davison
Lothian NHS Board is the common name of Lothian Health Board

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

12/SS/0089:	Please quote this number on all correspondence
--------------------	---

Yours sincerely



Dr Janet Andrews
Chair

E-mail: Sandra.Wyllie@nhslothian.scot.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *N/A. R&D contact not specified in database.*
 Marianne Laird

APPENDIX 9: Participation information sheet and consent form for intervention recruitment round one



GERIATRIC MEDICINE
Clinical and Surgical Sciences

SCHOOL of CLINICAL SCIENCES
and COMMUNITY HEALTH

The University of Edinburgh
Room S1642
Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh EH16 4SA

Secretaries: Mrs M Harding

Testing a behavioural change intervention to increase walking after stroke

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Part 1

What is the purpose of this study?

Stroke survivors are often advised to increase their physical activity. Walking is one of the easiest ways to increase physical activity. One possible way to increase walking is to use a step counter. These are small devices, worn on the body, which tells the user how many steps they have walked. We want to find out whether giving a step counter in addition to personalised weekly

step targets, support, motivation and advice will encourage stroke survivors to increase their walking.

Why have I been chosen to take part?

You have been chosen to take part because you have recently had a stroke. This study will recruit stroke survivors throughout Edinburgh and The Lothians over a 2 month period.

Do I have to take part?

It is up to you to decide whether or not to take part. The researcher will discuss the study with you and answer any questions you may have. You will be given this information sheet and at least 24 hours to decide if you wish to participate in the study. If you decide to take part, you will keep this information sheet and sign a consent form. If you decide to take part, you are free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you receive.

What will happen to me if I take part?

The researcher will visit you on the ward shortly before you go home.

We will ask you to walk for 2 minutes with a step counter attached to your clothing, above your hip. The 2 minute walk will ensure the step counter accurately detects the number of steps you walk. As long as the step counter detects 70% of your steps, you will be eligible to take part in the study.

We will gather information from your medical notes and from the team looking after you, about the type of stroke you have had and how it has affected you. We will ask you to complete five short questionnaires and perform a straightforward test to measure your balance and mobility. This test will look at your walking speed and ask you to perform different balance tests.

At discharge from hospital

You will be given a step counter to take home. We will ask you to record the number of steps you walk each day in a diary. The step counter will be worn daily attached to your clothing, above your hip. During this first week home you will also wear an

accelerometer. An accelerometer is a small device that will be attached to your thigh. The accelerometer records how much time you spend being physically active.

After this first week the researcher will visit you at home. At this visit the researcher will discuss how you have found using the step counter and go through a booklet with you. The booklet will help keep you motivated to increase your walking, help you plan the goals you wish to achieve and help you involve your family and friends in your decision to increase your walking. Throughout the study you will continue to wear the step counter, recording your daily step count. At the end of the study you may keep the step counter if you wish.

Follow up

- The researcher will telephone you each week for the first month, and then fortnightly for the remaining 2 months. These telephone calls will be to answer any questions or concerns you have, set your weekly step target and help maintain your motivation.
- One-two months after the initial visit the researcher will organise a group meeting. This is optional and you do not have to attend if you would prefer not to. At this meeting you can discuss walking with other participants and find out how they are progressing with their walking. The researcher will convene the meeting. The meeting will last approximately 1 hour and be held at The Clinical Research Facility at the Royal Infirmary of Edinburgh. Travel expenses will be reimbursed or we can arrange transport to and from the Royal Infirmary for you.
- You will also wear the accelerometer in the final week of the study. Physical activity data will be downloaded from the accelerometer onto a computer and compared with the first week of the study. This will help us to determine if the intervention helps increase physical activity.
- After the final week, we will ask you to come back into The Clinical Research Facility at the Royal Infirmary of Edinburgh. At this visit you will be asked to repeat four of the short questionnaires and the balance and mobility tests. This should take no more than 30 minutes. Travel expenses will be reimbursed or we can arrange transport to and from The Royal Infirmary for you.

What do I have to do?

There are no lifestyle restrictions.

What are the possible benefits of taking part?

Some participants may find it helpful to talk to someone about their symptoms after a stroke. The information we get from the study may help us to better treat patients with stroke in the future.

What are the possible disadvantages and risks of taking part?

We do not envisage any particular risks to your taking part. When walking, it is possible to develop aching and stiffness in your muscles or become tired. This should improve as you become more active.

What happens when the research study stops?

We will analyse the data and publish it in a journal. It will not be possible to identify you from the publication. Once the study has finished, we will send all study participants a newsletter describing the results of the study.

For further information, please see Part 2 of this information sheet.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

Contact Details

For further information, please contact Dr Gillian Mead, Consultant Stroke Physician, who is leading the study. Her phone number is 0131 242 6481 and her email address is Gillian.e.mead@ed.ac.uk.

If you have any concerns about the study, please contact Dr Mead in the first instance.

If you would like to discuss this study with someone independent of the study team please contact: Dr Susan Shenkin, Senior Clinical Lecturer, on 0131 242 6481

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if relevant new information becomes available?

If new information relevant to this project becomes available during the course of study, we will let you know about this.

What will happen if I don't want to carry on with the study?

If you decide at any time throughout the study that you do not want to complete the study, you can withdraw from the study. However, if you do decide to withdraw, we would like to keep any data which we have already collected.

What if there is a problem?

If you have a complaint about your treatment by members of staff (doctors, nurses etc) you should complain through the usual NHS complaints system.

If you have a complaint about the research you are involved in, you should complain to Dr Mead in the first instance. If there is a reportable serious adverse event, Dr Mead will report this to the sponsor of the study (NHS Lothian and University of Edinburgh).

Complaints

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (0131 242 6481). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure.

NHS Lothian Complaints Team
2nd Floor

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131 465 5708

Harm

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against (NHS Lothian or University of Edinburgh) but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

The University of Edinburgh has insurance. You may be able to make a claim.

Will my taking part in this study be kept confidential?

Our procedures for handling, processing, storage and destruction of their data are compliant with the Data Protection Act 1998.

We will obtain your permission to access your medical records and to collect data about you during the course of the study.

Information about you will be collected onto paper forms. These will be stored securely in a locked filing cabinet, in a locked office at the Royal Infirmary hospital. Dr Mead will be in charge of the data. The research team will be authorised to have access to the data. The sponsors of the research (University of Edinburgh and NHS Lothian), regulatory authorities will have access, as necessary, to view the data for monitoring the quality of research. All will have a duty of confidentiality to you. Nothing that could reveal your identity will be disclosed outside the research site. Data which identifies you as an individual will be destroyed 12 months after the end of the study.

After we have collected data from each visit, the data will be entered onto a computer database, held at the University of Edinburgh. When this is done, you will be given a unique code number, so that you cannot be identified by the information stored on the computer data base.

You have the right to check the accuracy of data held about you and correct any errors.

Involvement of the General Practitioner/Family doctor (GP)

Your own general practitioner will be informed about your participation in the study. We will write in your medical records that you have agreed to take part.

What will happen to the results of the research study?

The results of the study will be published in medical journals. We will also send a report to The Stroke Association. If you would like to see the results, please ask and we can make sure that you are sent a copy. You will not be identified in any report or publication. It will not be possible to identify you from this publication.

Who is organising and funding the research?

The Stroke Association is funding the research. The University of Edinburgh and NHS Lothian are co-sponsors of the research and are overseeing it. Dr Mead who is the Principal Investigator is in charge of the running of the study. She is not being paid for including you in the study. The study is conducted in collaboration with The University of Aberdeen, Newcastle University and Glasgow Caledonian University.

Who has reviewed the study?

This study has been given a favourable ethical opinion by the South East Scotland Research Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.

Study Number:
Patient Identification Number for this study

CONSENT FORM

**Title of Project: Testing a behavioural change intervention
to increase walking after stroke**

Name of Researcher: Dr Gillian Mead

Please initial box

1. I confirm that I have read and understand the information sheet dated 13/06/2012 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from University of Edinburgh, from regulatory authorities or from NHS Lothian, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that I must pass the step counter screening to be fully eligible for the study. ☐
5. I agree to my GP being informed of my participation in the study. ☐
6. I agree to take part in the above study. ☐

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

APPENDIX 10: Updated participant information sheet, consent form and participant booklets for recruitment round two



GERIATRIC MEDICINE
Clinical and Surgical Sciences

SCHOOL of CLINICAL SCIENCES
and COMMUNITY HEALTH

The University of Edinburgh
Room S1642
Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh EH16 4SA

Secretaries: Mrs M Harding

Testing a behavioural change intervention to increase walking after stroke

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Part 1

What is the purpose of this study?

Stroke survivors are often advised to increase their physical activity. Walking is one of the easiest ways to increase physical activity. One possible way to increase walking is to use a step counter. These are small devices, worn on the body, which tells the user how many steps they have walked. However, step counters do not detect steps in everyone. Another way to monitor

the amount of walking is to use a diary to record how much time is spent walking each day. We want to find out whether giving a step counter (or a diary to record time spent walking outdoors) in addition to personalised weekly step targets, support, motivation and advice will encourage stroke survivors to increase their walking.

Why have I been chosen to take part?

You have been chosen to take part because you have recently had a stroke. This study will recruit stroke survivors throughout Edinburgh and The Lothians over a 6 month period.

Do I have to take part?

It is up to you to decide whether or not to take part. The researcher will discuss the study with you and answer any questions you may have. You will be given this information sheet and at least 4 hours to decide if you wish to participate in the study. If you decide to take part, you will keep this information sheet and sign a consent form. If you decide to take part, you are free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you receive.

What will happen to me if I take part?

The researcher will visit you on the ward shortly before you go home.

You will be asked to walk for 2 minutes with a step counter attached to your clothing, above your hip. The 2 minute walk will determine if the step counter accurately detects the number of steps you walk. If the step counter detects 70% of your steps, you will be given the step counter to take home with you. If the step counter does not detect 70% of steps, we will ask you to keep a diary to record how many minutes you spend walking outdoors each day.

We will gather information from your medical notes and from the team looking after you, about the type of stroke you have had and how it has affected you. We will ask you to complete five short questionnaires and perform a straightforward test to measure your balance and mobility. This test will look at your walking speed and ask you to perform different balance tests.

At discharge from hospital

We will ask you to record the number of steps you walk or the time you spend walking outdoors each day in a diary. If you take a step counter home, this will be worn daily attached to your clothing, above your hip. During the first week home you will also wear an accelerometer. An accelerometer is a small device that will be attached to your thigh. The accelerometer records how much time you spend being physically active.

After this first week the researcher will visit you at home. At this visit the researcher will discuss how you have found using the step counter (if applicable) and go through a booklet with you. The booklet will help keep you motivated to increase your walking, help you plan the goals you wish to achieve and help you involve your family and friends in your decision to increase your walking. At the end of the study if you have been using the step counter you may keep it if you wish.

Follow up

- The researcher will telephone you each week for the first month, and then fortnightly for the remaining 2 months. These telephone calls will be to answer any questions or concerns you have, set your weekly walking targets and help maintain your motivation.
- One-two months after the initial visit the researcher will organise a group meeting. This is optional and you do not have to attend if you would prefer not to. At this meeting you can discuss walking with other participants and find out how they are progressing with their walking. The researcher will convene the meeting. The meeting will last approximately 1 hour and be held at The Clinical Research Facility at the Royal Infirmary of Edinburgh. Travel expenses will be reimbursed or we can arrange transport to and from the Royal Infirmary for you.
- You will also wear the accelerometer in the final week of the study. Physical activity data will be downloaded from the accelerometer onto a computer and compared with the first week of the study. This will help us to determine if the intervention helps increase physical activity.
- After the final week, we will ask you to come back into The Clinical Research Facility at the Royal Infirmary of

Edinburgh. At this visit you will be asked to repeat four of the short questionnaires and the balance and mobility tests. This should take no more than 30 minutes. Travel expenses will be reimbursed or we can arrange transport to and from The Royal Infirmary for you.

What do I have to do?

There are no lifestyle restrictions.

What are the possible benefits of taking part?

Some participants may find it helpful to talk to someone about their symptoms after a stroke. The information we get from the study may help us to better treat patients with stroke in the future.

What are the possible disadvantages and risks of taking part?

We do not envisage any particular risks to your taking part. When walking, it is possible to develop aching and stiffness in your muscles or become tired. This should improve as you become more active.

What happens when the research study stops?

We will analyse the data and publish it in a journal. It will not be possible to identify you from the publication. Once the study has finished, we will send all study participants a newsletter describing the results of the study.

For further information, please see Part 2 of this information sheet.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

Contact Details

For further information, please contact Prof Gillian Mead, Consultant Stroke Physician, who is leading the study. Her phone number is 0131 242 6481 and her email address is Gillian.e.mead@ed.ac.uk.

If you have any concerns about the study, please contact Prof Mead in the first instance.

If you would like to discuss this study with someone independent of the study team please contact: Dr Susan Shenkin, Senior Clinical Lecturer, on 0131 242 6481

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if relevant new information becomes available?

If new information relevant to this project becomes available during the course of study, we will let you know about this.

What will happen if I don't want to carry on with the study?

If you decide at any time throughout the study that you do not want to complete the study, you can withdraw from the study. However, if you do decide to withdraw, we would like to keep any data which we have already collected.

What if there is a problem?

If you have a complaint about your treatment by members of staff (doctors, nurses etc) you should complain through the usual NHS complaints system.

If you have a complaint about the research you are involved in, you should complain to Prof Mead in the first instance. If there is a reportable serious adverse event, Prof Mead will report this to the sponsor of the study (NHS Lothian and University of Edinburgh).

Complaints

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (0131 242 6481). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure.

NHS Lothian Complaints Team
2nd Floor
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131 465 5708

Harm

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against (NHS Lothian or University of Edinburgh) but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

The University of Edinburgh has insurance. You may be able to make a claim.

Will my taking part in this study be kept confidential?

Our procedures for handling, processing, storage and destruction of their data are compliant with the Data Protection Act 1998. We will obtain your permission to access your medical records and to collect data about you during the course of the study.

Information about you will be collected onto paper forms. These will be stored securely in a locked filing cabinet, in a locked office at the Royal Infirmary hospital. Prof Mead will be in charge of the data. The research team will be authorised to have access to the data. The sponsors of the research (University of Edinburgh and NHS Lothian), regulatory authorities will have access, as necessary, to view the data for monitoring the quality of research. All will have a duty of confidentiality to you. Nothing that could reveal your identity will be disclosed outside the research site.

Data which identifies you as an individual will be destroyed 12 months after the end of the study.

After we have collected data from each visit, the data will be entered onto a computer database, held at the University of Edinburgh. When this is done, you will be given a unique code number, so that you cannot be identified by the information stored on the computer data base.

You have the right to check the accuracy of data held about you and correct any errors.

Involvement of the General Practitioner/Family doctor (GP)

Your own general practitioner will be informed about your participation in the study. We will write in your medical records that you have agreed to take part.

What will happen to the results of the research study?

The results of the study will be published in medical journals. We will also send a report to The Stroke Association. If you would like to see the results, please ask and we can make sure that you are sent a copy. You will not be identified in any report or publication. It will not be possible to identify you from this publication.

Who is organising and funding the research?

The Stroke Association is funding the research. The University of Edinburgh and NHS Lothian are co-sponsors of the research and are overseeing it. Prof Mead who is the Principal Investigator is in charge of the running of the study. She is not being paid for including you in the study. The study is conducted in collaboration with The University of Aberdeen, Newcastle University and Glasgow Caledonian University.

Who has reviewed the study?

This study has been given a favourable ethical opinion by the South East Scotland Research Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.

Study Number:

Patient Identification Number for this study



GERIATRIC MEDICINE
Clinical and Surgical Sciences
SCHOOL of CLINICAL SCIENCES
and COMMUNITY HEALTH
The University of Edinburgh
Room S1642
Royal Infirmary of Edinburgh
51 Little France Crescent
Edinburgh EH16 4SA
Secretaries: Mrs M Harding

CONSENT FORM

Title of Project: Testing a behavioural change intervention to increase walking after stroke

Name of Researcher: Prof Gillian Mead

Please initial box

1. I confirm that I have read and understand the information sheet dated 09/12/2013 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from University of Edinburgh, from regulatory authorities or from NHS Lothian, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree to my GP being informed of my participation in the study. ☐

5. I agree to take part in the above study. ☐

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

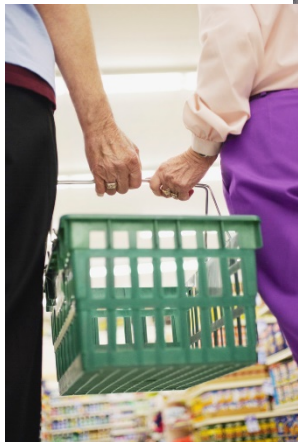
Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

Minutes walking group:

Increasing walking after stroke

Participant booklet





The research team would like to thank The Stroke Association for funding this research and The University of Edinburgh and NHS Lothian for their support.



Contents

The aim of this booklet is to help you increase your walking.
You and the researcher will work through this booklet together
and plan how to increase your walking.

	Page number
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Why walking is important	4
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Action planning and coping planning	12
Section 5	
Walking Diary	22
Section 6	
Study feedback	
(complete at the end of the study)	38

Section 1

This section gives you information about the benefits of increasing your walking after a stroke. This section also covers any difficulties you might face as you try to increase your walking.

Why walking is important

Stroke survivors are often advised to do more physical activity. Walking is one of the easiest ways to do this. You can enjoy walking alone or with someone else. You can walk when you want, where you want and without much planning or special equipment.

Increasing walking may

- boost your energy levels
- lower your blood pressure and cholesterol, which may reduce the risk of a further stroke
- control your body weight
- prevent walking becoming difficult in the future
- increase your fitness
- strengthen your bones

However you may find that increased walking may

- make you tired, especially if you begin doing too much, too soon
- cause muscle stiffness and aching. This tends to be temporary and is less likely to occur as your body becomes used to doing more walking

The researcher will have checked with your medical team that it is safe for you to take part in this study (there can be small risks involved when increasing walking, including falls and the risk of a heart attack). When you walk, please follow the advice from your own doctor/physiotherapist e.g. if you walk with an aid (e.g. Zimmer frame) please continue to do so whilst taking part in this study. If you begin to feel unwell when walking, please seek advice from your own doctor.

Importantly, in the longer term, we know that walking is good for your health and may reduce the risk of stroke and heart attack.

Section 2

This section is about how your family and friends can help you increase your walking. For each question circle the appropriate answer/s and write any comments.

Support from family and friends

How would your family and friends feel if you increased your walking?

Happy	Comments
Sad	
Calm	
Worried	
Supportive	
Unsupportive	

Would your family and friends support you increasing your walking?

Yes definitely	Comments
Yes probably	
Probably not	
Definitely not	
Unsure	

Would your family and friends increase their own walking with you?

Yes definitely Yes probably Probably not Definitely not Unsure	Comments
--	----------

Would your family and friends go walking with you?

Yes definitely Yes probably Probably not Definitely not Unsure	Comments
--	----------

Section 3

The following section contains an information sheet for your family and friends. It can be removed from the booklet and given to your friends and family members. If you need additional copies of the information sheet, let the researcher know.

Family Information Sheet

Stroke survivors are often advised to do more physical activity. Walking is one of the easiest ways to do this. Walking improves health and fitness.

Increasing walking may

- boost energy levels
- lower blood pressure and cholesterol, which may reduce the risk of a further stroke
- control body weight
- prevent walking becoming difficult in the future
- increase fitness
- strengthen bones

..... has decided to participate in a 3 month study.

The study aims to increase walking.

..... will be given weekly walking targets. The researcher and will plan how to meet these walking targets.

We will provide with motivation and support throughout the study to help boost his/her confidence.

How you can support

Sometimes it can be difficult to increase walking. If you encourage to walk, this may help him/her to continue to increase their walking.

If you try to increase your own walking, this could also help motivate and increase his/her confidence to take part in physical activity. If you walk with this may also help you feel less anxious about their safety when they are out and about.

If you have any questions please contact **Sarah Nicholson** on **0131 242 6940**.

Section 4

This section will help you plan how to increase your walking. It will also help you to think about any difficulties you may face. In this section, you will record how confident you feel about increasing your walking.

Action planning and coping planning

Believing you are capable of increasing your walking is important. You may find it helpful to plan how and when you will increase your walking. Think about the challenges you may encounter when trying to carry out what you plan (coping plans). This will help you to deal with difficulties if they arise.

Action plans and coping plans will be filled in with the help of the researcher. You do not need to fill in all 5 goals at the start of the study. As you progress through the study you may wish to add more goals or change your existing goals.

Below is an example goal.

Example goal: To walk to the shops for a newspaper				
What? Describe what you will do to achieve your goal	When? Describe the time of day and duration	How? Specify the situation	Potential problems that could happen?	How can I tackle these problems?
<i>1. Walk to the end of the street and back</i> <i>2. Walk to post box and back</i> <i>3. Walk to shops and back</i>	<i>First thing in morning after breakfast.</i>	<i>Ask friend to walk with me</i>	<i>1. Too tired to go out walking</i> <i>2. Friend can't walk with me.</i>	<i>1. Rest, but try and walk tomorrow</i> <i>2. Ask other friends or family members if they can walk with me.</i>

Goal 1				
What?	When?	How?	Potential problems?	How can I tackle these problems?

Goal 2				
What?	When?	How?	Potential problems?	How can I tackle these problems?

Goal 3				
What?	When?	How?	Potential problems?	How can I tackle these problems?

Goal 4				
What?	When?	How?	Potential problems?	How can I tackle these problems?

Goal 5				
What?	When?	How?	Potential problems?	How can I tackle these problems?

Your feelings

We now want to look at how confident you feel about walking. Having confidence in your own walking is important. Believing you are capable of increasing your walking can help you to achieve your walking goals.

To determine your confidence in increasing your walking during the study, please circle the appropriate answers for the following sentences.

I intend to increase my walking over the study period?

Strongly agree

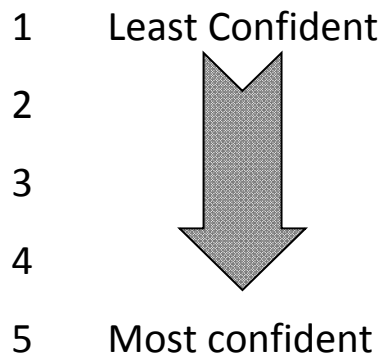
Agree

Neither agree nor disagree

Disagree

Strongly disagree

I am confident I will be able to increase my walking over the study period?



To help achieve your goals you may need help from family or friends to take you out and walk with you. Here are some suggestions that might help with this

- encourage a family member(s) to go walking with you
- try to share driving amongst different family members and friends
- ask your stroke nurse about any local community stroke classes you could attend that offer transport
- enquire about volunteer driver services (e.g. WRVS Edinburgh Community Transport Service)

Many stroke survivors prefer walking outside. However, if you can't walk outside, walking around your house or garden may also help you achieve your walking targets.

Section 5

In this section, please record the time you spend walking each day. This will allow you to see the progress you make during the study. If you did not meet your walking target, please make notes on each diary entry which might explain the reasons (i.e. feeling unwell, poor weather). These notes will help the research team understand the difficulties stroke survivors face when trying to increase walking. If you wish, family members or friend can help you fill out your daily walking diary.

Walking Diary

This walking diary will allow you to track the progress of your walking and see the improvements you have made.

We would also like you to record how many minutes you spend walking outdoors each day. After each period of walking outdoors please record the number of minutes you spent walking. Please record the total minutes you spend walking outdoors in the diary each night before bed.

If you miss a day do not worry, but try not to forget the next day.

Repeated for weeks 2-7

Date	Approximately how long did you walk outdoors for today? (minutes)	Approximately how long did you walk indoors for today? (minutes)	Notes
Total weekly walking (minutes):			
Walking target (minutes):			

Looking back

You are now half way through the 3 month study. Hopefully, you have already achieved some of your goals and the time spent walking each week has increased. If this is not the case, do not worry. There are still 6 weeks left of the study, when you can try and increase your walking.

Take a moment to look back at the barriers you felt at the beginning of the study. Have you managed to overcome any of these? Have any of these barriers changed since the start of the study?

Has your intention to increasing walking altered since the beginning of the study? Circle the appropriate answer below

I intend to increase my walking over the rest of the study period?

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Has your confidence to increasing walking altered since the beginning of the study? Circle the appropriate answer below.

I am confident I will be able to increase my walking over the rest of the study period?

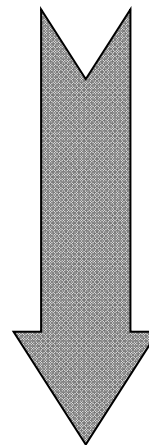
1 Least Confident

2

3

4

5 Most confident



Continue to look back through this booklet to remind yourself of what you have already achieved. Some days may be more difficult than others. Continue to monitor your walking for the remaining 6 weeks. This will help you maintain your walking in the future.

Repeated for week 8-13

Date	Approximately how long did you walk outdoors for today? (minutes)	Approximately how long did you walk indoors for today? (minutes)	Notes
Total weekly walking (minutes):			
Walking target (minutes):			

Congratulations, you have now reached the end of the study.

The researcher should have already contacted you to arrange another visit into The Clinical Research Facility at The Royal Infirmary of Edinburgh. This visit should happen within the next week. The purpose of this visit will be to repeat the 5 questionnaires and leg function test.

Section 6

Study feedback

Now that you have completed the 3 month study, please take a couple of minutes to fill out this feedback form. The information we receive will help us improve future studies for stroke survivors.

Do you think this study was

Too long?

Too short?

Just the right length?

How easy did you find recording your time spent walking each day?

Very easy

Quite easy

Neither easy nor difficult

Quite difficult

Very difficult

How easy was booklet to follow?

Very easy

Quite easy

Neither easy nor difficult

Quite difficult

Very difficult

Were the telephone calls from the researcher

Too frequent?

Not frequent enough?

About right?

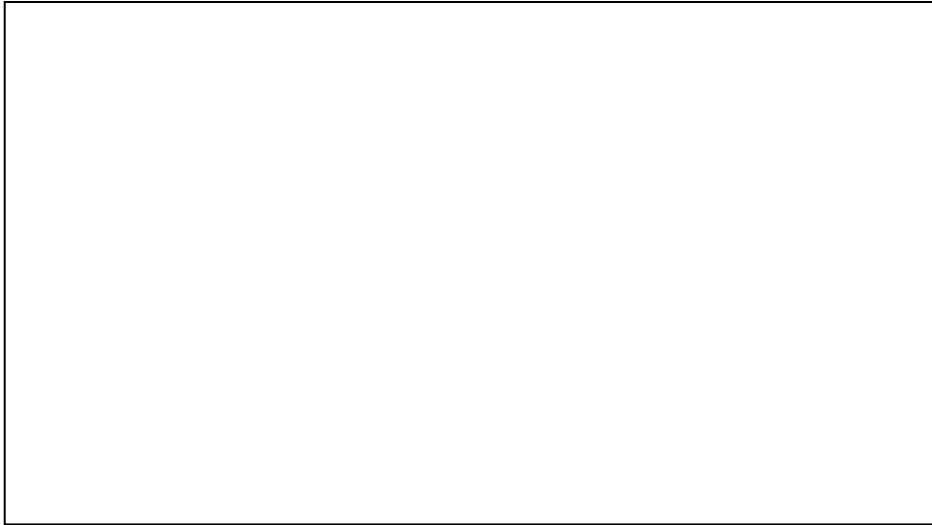
Were you satisfied with the help and advice the intervention
gave you?

1 2 3 4 5 6 7 8 9 10

(totally unsatisfied)

(totally satisfied)

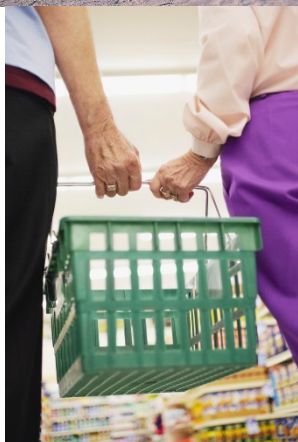
Additional comments to the research team about the study

A large, empty rectangular box with a thin black border, intended for additional comments to the research team about the study.

Pedometer group:

Increasing walking after stroke

Participant booklet





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- prevent walking becoming difficult in the future
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- strengthen your bones

However you may find that increased walking may

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Importantly, in the longer term, we know that walking is good for your health and may reduce the risk of stroke and heart attack.

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This section is about how your family and friends can help you increase your walking. For each question circle the appropriate answer/s and write any comments.

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Unsupportive	

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Probably not	
Definitely not	
Unsure	

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--	----------

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We will provide with motivation and support throughout the study to help boost his/her confidence.

How you can support

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If you try to increase your own walking, this could also help motivate and increase his/her confidence to take part in physical activity. If you walk with this may also help you feel less anxious about their safety when they are out and about.

If you have any questions please contact **Sarah Nicholson** on **0131 242 6940**.

Section 4

This section will help you plan how to increase your walking. It will also help you to think about any difficulties you may face. In this section, you will record how confident you feel about increasing your walking.

Action planning and coping planning

Believing you are capable of increasing your walking is important. You may find it helpful to plan how and when you will increase your walking. Think about the challenges you may encounter when trying to carry out what you plan (coping plans). This will help you to deal with difficulties if they arise.

Action plans and coping plans will be filled in with the help of the researcher. You do not need to fill in all 5 goals at the start of the study. As you progress through the study you may wish to add more goals or change your existing goals.

Below is an example goal.

Example goal: To walk to the shops for a newspaper				
What? Describe what you will do to achieve your goal	When? Describe the time of day and duration	How? Specify the situation	Potential problems that could happen?	How can I tackle these problems?
<i>1. Walk to the end of the street and back</i> <i>2. Walk to post box and back</i> <i>3. Walk to shops and back</i>	<i>First thing in morning after breakfast.</i>	<i>Ask friend to walk with me</i>	<i>1. Too tired to go out walking</i> <i>2. Friend can't walk with me.</i>	<i>1. Rest, but try and walk tomorrow</i> <i>2. Ask other friends or family members if they can walk with me.</i>

Goal 1				
What?	When?	How?	Potential problems?	How can I tackle these problems?

Goal 2				
What?	When?	How?	Potential problems?	How can I tackle these problems?

Goal 3				
What?	When?	How?	Potential problems?	How can I tackle these problems?

Your feelings

We now want to look at how confident you feel about walking. Having confidence in your own walking is important. Believing you are capable of increasing your walking can help you to achieve your walking goals.

To determine your confidence in increasing your walking during the study, please circle the appropriate answers for the following sentences.

I intend to increase my walking over the study period?

Strongly agree

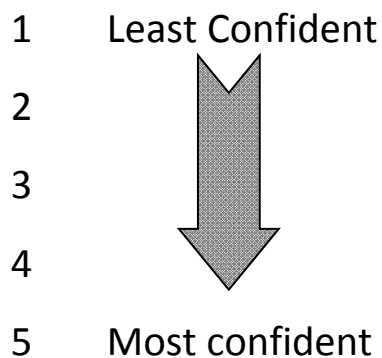
Agree

Neither agree nor disagree

Disagree

Strongly disagree

I am confident I will be able to increase my walking over the study period?



To help achieve your goals you may need help from family or friends to take you out and walk with you. Here are some suggestions that might help with this

- encourage a family member(s) to go walking with you
- try to share driving amongst different family members and friends

- ask your stroke nurse about any local community stroke classes you could attend that offer transport
- enquire about volunteer driver services (e.g. WRVS Edinburgh Community Transport Service)

Many stroke survivors prefer walking outside. However, if you can't walk outside, walking around your house or garden may also help you achieve your walking targets.

Section 5

In this section, please record the time you spend walking each day. This will allow you to see the progress you make during the study. If you did not meet your walking target, please make notes on each diary entry which might explain the reasons (i.e. feeling unwell, poor weather). These notes will help the research team understand the difficulties stroke survivors face when trying to increase walking. If you wish, family members or friend can help you fill out your daily walking diary.

Step Diary

This step diary will allow you to track the progress of your walking and see the improvements you have made.

5. Each morning, as soon as you get up, put on the step counter
6. Leave it on all day
7. At bedtime remove the step counter
8. Record the number of steps from the step counter into your step diary

If you miss a day do not worry, but try not to forget the next day.

We would also like you to record how many minutes you spend walking outdoors each day. After each period of walking outdoors please record the number of minutes you spent walking. Please record the total minutes you spend walking outdoors in the diary each night before bed.

Repeated weeks 2-7

Pedometer target for this week:				
Date	Approximately how long did you walk outdoors for today? (minutes)	Approximately how long did you walk indoors for today? (minutes)	Pedometer reading	Notes
Total weekly walking:				

Looking back

You are now half way through the 3 month study. Hopefully, you have already achieved some of your goals and the time spent walking each week has increased. If this is not the case, do not worry. There are still 6 weeks left of the study, when you can try and increase your walking.

Take a moment to look back at the barriers you felt at the beginning of the study. Have you managed to overcome any of these? Have any of these barriers changed since the start of the study?

Has your intention to increasing walking altered since the beginning of the study? Circle the appropriate answer below

I intend to increase my walking over the rest of the study period?

Strongly agree

Agree

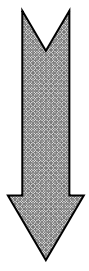
Neither agree nor disagree

Disagree

Strongly disagree

Has your confidence to increasing walking altered since the beginning of the study? Circle the appropriate answer below.

I am confident I will be able to increase my walking over the rest of the study period?

- | | |
|---|-----------------|
| 1 | Least Confident |
| 2 | |
| 3 | |
| 4 | |
| 5 | Most confident |
- 

Continue to look back through this booklet to remind yourself of what you have already achieved. Some days may be more difficult than others. Continue to monitor your walking for the remaining 6 weeks. This will help you maintain your walking in the future.

Repeated weeks 8-13

Pedometer target for this week:				
Date	Approximately how long did you walk outdoors for today? (minutes)	Approximately how long did you walk indoors for today? (minutes)	Pedometer reading	Notes
Total weekly walking:				

Congratulations, you have now reached the end of the study.

The researcher should have already contacted you to arrange another visit into The Clinical Research Facility at The Royal Infirmary of Edinburgh. This visit should happen within the next week. This purpose of this visit will be to repeat the 5 questionnaires and leg function test.

Section 6

Study feedback

Now that you have completed the 3 month study, please take a couple of minutes to fill out this feedback form. The information we receive will help us improve future studies for stroke survivors.

Do you think this study was

Too long?

Too short?

Just the right length?

How easy did you find recording your time spent walking each day?

Very easy

Quite easy

Neither easy nor difficult

Quite difficult

Very difficult

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